



Guiding Principles

Successfully Supporting and Enrolling People with Disabilities in a Redesigned System for Long Term Supports and Services¹

Designing and operating a redesigned system for children and adults with disabilities poses unique challenges given the highly diverse, wide ranging health and long-term support needs of the disability population. Those challenges multiply when a state attempts to create a unified system of acute health and long-term services. If service delivery policies are well designed and effectively implemented there is potential to achieve cost savings by improving health outcomes and eliminating inefficiencies, not by reducing the quality or availability of care.

In the current state and federal policy environment where reducing public expenditures is a primary aim of public policy, there is a significant risk that vulnerable people with disabilities will be the victims of poorly conceived and executed public policies that fail to meet their needs. If such results are to be avoided, it is essential that the principles articulated below are meticulously observed in designing and carrying out initiatives involving people with chronic disabilities. Done right, all stakeholders will benefit.

I. PERSONAL EXPERIENCE AND OUTCOMES

A. COMMUNITY LIVING

PRINCIPLE #1: The central organizing goal of system reform must be to assist individuals with disabilities to live full, healthy, participatory lives in the community.

B. PERSONAL CONTROL

PRINCIPLE #2: Systems must be designed to support and implement person-centered practices, consumer choice, and consumer-direction.

C. EMPLOYMENT

PRINCIPLE #3: For non-elderly adults with disabilities employment is a critical pathway toward independence and community integration. Working age enrollees and older Texans who want to work must receive the supports necessary to secure and retain competitive employment.

D. SUPPORT FOR FAMILY CAREGIVERS

PRINCIPLE #4: Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.

¹ Adapted from the National Council on Disability - An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. Adopted by Disability Policy Consortium – November 27, 2012

The Texas Disability Policy Consortium is a group of advocacy organizations working for fair and equitable public policy for Texans with disabilities. The Consortium strives to achieve the development and full implementation of public policy that promotes and supports the rights, inclusion, integration, and independence of Texans with disabilities. The Consortium is unique in that it provides an ongoing forum for discussion and opportunity to unite voices on important disabilities issues in Texas. Consortium members may take independent positions as appropriate on specific policies as they develop.



II. REDESIGNING AND MANAGING A NEW SYSTEM

A. STAKEHOLDER INVOLVEMENT

PRINCIPLE #5: Texas must ensure that key disability stakeholders -- including individuals with disabilities, family members, support agency representatives, and advocates -- are fully engaged in designing, implementing and monitoring the outcomes and effectiveness of services and service delivery systems.

B. CROSS-DISABILITY, LIFE-SPAN FOCUS

PRINCIPLE #6: The service delivery system must be capable of addressing the diverse needs of all enrollees on an individualized basis, including children, adolescents and adults with physical disabilities, intellectual and developmental disabilities, traumatic brain injuries, mental illnesses, substance abuse disorders, and other types of severe, chronic disabilities.

C. READINESS ASSESSMENT & PHASE-IN SCHEDULE

PRINCIPLE #7: Texas should complete a readiness assessment before deciding when and how various sub-groups of people with disabilities should be enrolled. A phase-in schedule in turn should be based on the results of this assessment.

D. PROVIDER NETWORKS

PRINCIPLE #8: The network of providers enrolled should include those who furnish health care, behavioral health and, where applicable, long term supports. The network must encompass both providers of institutional and home and community-based supports. Each network should have sufficient numbers of qualified providers in each specialty area to allow participants to choose among alternatives. The direct support workers in the system must be compensated adequately to address the recruitment and retention of qualified staff and to pay for career ladder advancement with additional expertise and competencies.

E. TRANSITIONING TO COMMUNITY-BASED SERVICES

PRINCIPLE #9: Texas' plan to redesign long-term services and supports in must include providers of institutional programs as well as providers of home and community-based supports within the plan's scope of services. This requirement should be built into the "terms and conditions" on any Texas waiver proposal.

F. EXPERTISE

PRINCIPLE #10: The existing reservoir of disability-specific expertise, both within and outside of state government, should be fully engaged in designing service delivery and financing strategies and in performing key roles within the restructured system.

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F. COMPETENCY

PRINCIPLE #11: Responsibility for day-to-day oversight of the service delivery system must be assigned to highly qualified state and federal governmental personnel with the decision-making authority necessary to proactively administer the system in the public interest.

H. CONTINUOUS INNOVATION

PRINCIPLE #12: The federal government and the states should actively promote innovation in long-term services and supports for people with disabilities.

I. MAINTENANCE OF EFFORT & REINVESTING SAVINGS

PRINCIPLE #13: Texas must commit to "maintenance of effort" provisions in seeking health and long-term service reform waivers. Savings achieved through reduced reliance on high-cost institutional care, reductions in unnecessary hospital admissions and improved coordination and delivery of services must be used to extend services and supports to unserved and underserved individuals with disabilities.

J. COORDINATION OF SERVICES & SUPPORTS

PRINCIPLE #14: Within a well-balanced service system, the delivery of primary and specialty health services must be effectively coordinated with any long-term services and supports that an individual might require.

III. OPERATING COMPONENTS

A. ASSISTIVE TECHNOLOGY & DURABLE MEDICAL EQUIPMENT

PRINCIPLE #15: Participants must have access to the durable medical equipment and assistive technology they need to function independently and live in the least restrictive setting.

B. QUALITY MANAGEMENT

PRINCIPLE #16: The state must have in place a comprehensive quality management system that not only ensures the health and safety of vulnerable beneficiaries but also measures the effectiveness of services in assisting individuals to achieve personal goals. To achieve quality, the public, individuals receiving services and their families must be involved in development of new program innovations and systems design, monitoring implementation, establishing and evaluating quality reporting measures and continuous quality improvement strategies.

IV. PARTICIPANT RIGHTS

A. CIVIL RIGHTS COMPLIANCE

PRINCIPLE #17: All health care services and supports must be furnished in ADA-compliant settings.

PRINCIPLE # 18: The system must be accessible, easily understood and transparent for individuals.

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B. CONTINUITY OF MEDICAL CARE

PRINCIPLE #19: Enrollees should be permitted to retain existing physicians and other health practitioners who are willing to adhere to plan rules and payment schedules.

C. DUE PROCESS

PRINCIPLE #20: Enrollees with disabilities should be fully informed of their rights and obligations as well as the steps necessary to access needed services.

D. GRIEVANCES & APPEALS

PRINCIPLE #21: Grievance and appeal procedures should be established that take into account physical, intellectual, behavioral and sensory barriers to safeguarding individual rights under the provisions of the service system as well as all applicable federal and state statutes.

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