

Components of a Model System of Care for People with Developmental Disabilities

Vision

All persons with developmental disabilities have access to health services that maximize their wellness and function.

Guiding Principle

Health care for people with developmental disabilities is interdisciplinary team-based care with patients and caregivers at the center of the team.

1. Provider Competency

Providers are knowledgeable about and sensitive to the needs of people with developmental disabilities, and have the information, resources and tools they need to provide quality services.

Key Strategies:

- Train and mentor (clinical knowledge, cultural competency, and communication) health care providers and staff
- Develop and implement use of electronic health records
- Remove physical and programmatic barriers (larger exam rooms, large print patient information, longer appointment times)
- Provide access to specialized allied health care providers and specialist consultation for primary care providers

2. Access to Quality Health Care

People with developmental disabilities are able to access individualized, community-based quality health care, including specialized physicians, psychiatrists, dentists, nurses, and allied health professionals.

Key Strategies:

- Provide access to information about where to go for health services
- Finance/reimburse health care services adequately
- Provide access to transportation
- Limit the size of patient load for clinicians (100-300 patients per FTE)
- Provide health care in natural settings (e.g., home, school, community agency, clinic)

3. Patient Support

People with developmental disabilities have the information and resources they need to obtain health services, comply with treatment and prescriptions, and maximize personal wellness and function.

Key Strategies:

- Educate patients, health care and service providers, as well as family members and caregivers, of patient health care rights and responsibilities, including support for self-determination
- Designate appropriate surrogate decision-makers (i.e., informed consent, confidentiality, restraint)
- Provide training and resources for caregivers
- Engage in transition planning
- Identify an individual health care plan team member responsible for monitoring of the health care plan and ensuring implementation of the plan (finding doctors, arranging funding for health care, asking for help when ill, scheduling routine and follow-up visits in an appropriate time frame, preparing for doctor's visit, getting to the doctor or being ready for the doctor on time, communicating with the doctor, cooperating with medical evaluations, making informed consent decisions including requesting a second opinion, and adhering to medical recommendations for general self-care and specific therapies)

4. Quality Assurance and Oversight

Stakeholders have access to the information they need to monitor and enhance the quality of services provided.

Key Strategies:

- Define health care outcomes and quality standards clearly
- Provide access to data necessary for evaluating quality of care and health care outcomes
- Provide access to information and research regarding promising models and practices
- Provide clear oversight and accountability for ensuring health care access and outcomes
- Loop back to provider training and curriculum

5. Public Engagement and Support

There is a broad understanding of the health care needs of people with developmental disabilities and support for change.

Key Strategies:

- Develop a shared vision and sense of responsibility among key stakeholder groups
- Identify and engage a champion/leadership
- Educate policymakers and public