19. DISABILITY AND SECONDARY CONDITIONS

Goal

Promote health and prevent secondary conditions among persons with disabilities, including eliminating disparities between persons with disabilities and the U.S. population.

Terminology

Health Promotion: The promotion of healthy lifestyles and a healthy environment, the prevention of health complications (medical secondary conditions) and further disabling conditions, the preparation of the person with a disability to understand and monitor his or her own health and health care needs, and the promotion of opportunities for participation in commonly held life activities.

People with disabilities: Those persons identified as having limitations in activities because of an impairment or health condition, usually defined as having a duration of at least 12 months. Activities include those that negatively influence participation in work, school, leisure, and family and community life, from simple to complex, including looking and listening, standing, walking, achieving mobility, performing personal care, communicating, learning, and engaging in related behaviors.

Overview

Healthcare is a basic right of all Americans. Healthcare coverage should not exclude people with disabilities based on preexisting conditions or through out-of-pocket expenses. Coverage and benefits must be portable and without lifetime caps. Work disincentives must be eradicated and comprehensive benefits packages must be guaranteed and specific.

Community health promotion should include people with disabilities in order to prevent secondary health conditions. Health promotion programs have been shown to be effective in reducing secondary conditions and outpatient physician visits among persons with disabilities. Many existing health promotion interventions already in place for the population at large are easily adaptable to the needs of people with disabilities.

The support needed by people with disabilities to make community living and selfdetermination possible comes not only from programs specifically designed to provide such supports, but comes naturally from friends, families, coworkers, classmates, neighbors and from other people and groups in the community. This makes inclusion a critical issue throughout the life span of an individual with disabilities and not limited to the educational years.

Kentucky is ranked 49th nationwide in the amount of funding for individuals with disabilities and spends 15 percent less than other southern states for this special population.

At this time, many individuals with disabilities are still separated and isolated from the community. Adequate protections are not uniformly in place to ensure their rights and safety. People with disabilities have no choice about where and with whom they live, about the kinds of work and activities they do, and about the people who assist them in their lives. They have little or no choice about the services and supports over their own resources.

Inclusion in educational activities with nondisabled peers is a crucial part of social and emotional health of children with disabilities. In order to insure successful integration, inclusion in regular classrooms must be done with appropriate supports.

Persons with disabilities are often disabled as much, if not more, by environmental barriers as by personal activity limitations. No surveillance data are available currently to evaluate the impact of environmental factors on participation.

Progress Toward Year 2000 Objectives

Healthy Kentuckians 2000 had no chapter addressing the health objectives for people with disabilities.

2010 Objectives

19.1. (Developmental) Ensure that 100 percent of healthcare policy and programs include or address the interests of individuals with disabilities.

Potential data sources: Kentucky Developmental Disabilities Council, Health Care Partnerships, Department for Public Health, Medicaid Program, Kentucky Disabilities Coalition, Commission for the Deaf and Hard of Hearing, Commission for Children with Special Health Care Needs (CCSHCN).

Implementation Strategy:

• Participate in a network of interested parties to influence state health care policies.

- Provide and expand networking opportunities for legislators, healthcare providers and educators, advocates and individuals with disabilities, such as the Legislative Breakfast to make sure personal stories are shared.
- Develop consultant positions for individuals with disabilities within the Cabinet for Health Services for the purposes of insuring input into development of policies, health promotion campaigns.
- Update background data for the disabilities populations. Include specific questions on disabilities on the Behavioral Risk Factor Surveillance System (BRFSS).
- Require Medicaid-managed care organizations (HMOs) to address quality assurance issues related to individuals with disabilities.

19.2. (Developmental) Ensure that 100 percent of Kentuckians with disabilities have the opportunity to participate to their fullest potential in community life.

Potential Data Sources: Kentucky Developmental Disabilities Council, Health Care Partnerships, Department for Public Health, BRFSS, Medicaid Program, Kentucky Disabilities Coalition, Commission for the Deaf and Hard of Hearing, CCSHCN.

Implementation Strategy:

- Update background data for the disabilities populations. Include specific questions on disabilities on the BRFSS.
- Initiate the development of a centralized interagency database that tracks and provides information on disability statistics, including recipient and waiting-list demographics, a breakdown of total dollars spent on services, and identification of specific services provided to individuals in the state.
- Advocate and assist in efforts to increase funding to level of need for Supported Living and other community based services.
- Develop a regional, community-based system of coordinated services to facilitate appropriate access to services, using person centered planning, similar to First Steps. Included in services would be case management, financial planning services, referral to therapies, housing assistance. Serving persons with disabilities in their community would lead to long term savings.

19.3. Increase to 75 percent the proportion of children with disabilities included with appropriate supports in regular education programs.

Baseline: 50 percent for Kentucky children 3-21 years of age in 1997.

Data Source: Kentucky Department of Education, Office of Special Education, CCSHCN.

Implementation Strategy:

- Support evaluation services for children between three and five to ensure transition and referral to appropriate therapies and services before kindergarten.
- Support special intensive training for all teachers and childcare workers to enable them to appropriately work with children with special needs within the classroom setting through conferences and inservices.
- Pre-service education for teachers special education issues will be woven into the whole curriculum.
- Survey school districts as to number of children in special education services and as to classroom setting.
- Increase public awareness on issues in education related to inclusion, transition, and assistive technologies and parents' and students' rights through training, education, and technical assistance.
- Support and continue the development of peer tutor network.
- Identify and disseminate information on accessible classroom modifications, assistive technology devices, and materials in alternative formats.
- Support the continued development of certification programs at the community college level, which will increase the number of associate degree people in related services professions.
- Increase public awareness of assistive technology and parents' and students' rights to assistive technology in the public schools.
- 19.4. (Developmental) Ensure that environmental factors are rated as barriers to participation at home or work and in the community by equal proportions of people with and without disabilities.
 - Access to buildings
 - Access to information, communication, and other devices and technology
 - Transportation
 - Perceived community attitudes
 - Governmental policies

Potential Data Sources: BRFSS, CDC, National Center for Chronic Disease Prevention and Health Promotion, Kentucky Disabilities Coalition, Kentucky Developmental Disabilities Council

Implementation Strategy:

- Support a study on the current status of available and accessible transportation for individuals with disabilities in Kentucky, including recommendations for improvement and a report to the Kentucky General Assembly.
- Advocate with the Kentucky Public Transportation Association to develop a system that allows effective transfers from one transportation system to another.

- In collaboration with Protection and Advocacy, develop and submit to the Governor, a plan and cost analysis that will make van lifts allowable under Medicaid, thereby supplanting current policies on ambulance service payments for medical appointments.
- Advocate for inclusion of information on the rights of pedestrians with disabilities in the state drivers' manual.
- Include the Participation and Environment portion of the Disability module of the BRFSS when it becomes available from the CDC.
- Advocate for the development of policies and practices that will improve community transportation in Kentucky's primary urban areas and resource centers (Lexington, Louisville, and Northern Kentucky.)
- Facilitate a plan and implementation for a statewide public transportation system that is accessible to all people with disabilities.
- Increase the supports for employment opportunities by augmenting the capacity of the Assistive Technology Loan Authority.
- Inform employers about assistive technology resources and how they can be used effectively in hiring and accommodating persons with disabilities.

References

- Kentucky DD Council, Three year State Plan and Objectives, Version #3
- Urban Research Institute, Services to Kentuckians with Developmental Disabilities 1990 Report of the Kentucky Developmental Disabilities Planning Council; Final Report
- United States Department for Health and Human Services. *Healthy People 2010*, January 2000.

Contributors

- Zaida Belendez, ND, RN, Nurse Consultant, Developmental Pediatric Programs, Department for Public Health, Chapter Coordinator
- Barbara Wright, Assistant Executive Director, Kentucky Developmental Disabilities Council
- Preston Lewis, Special Education Programs, Department of Education