

**Pennsylvania State Implementation Grant:
Integrating Systems and Services for
Children and Youth with Special Health Care Needs**

Federal Project Intent: The Maternal and Child Health Bureau (MCHB) has established that family and community participation and engagement are key to the development of effective, quality health systems and services. MCHB strongly supports when implementing any recommended evidence based practices, members of the populations for which the practice is intended, be included in the planning, implementation and evaluation of that practice. This approach would embrace families of children with special health care needs, youth with special health care needs and community representatives, including those of culturally and linguistically diverse backgrounds. The six program areas, which correlate with the six core MCHB outcomes, addressed in this project are: 1) Family Professional Partnerships/Cultural Competence, 2) Medical Home, 3) Health Insurance and Financing, 4) Community Integrated Services, 5) Early and Continuous Screening, 6) Healthy and Ready to Work. (excerpts taken from NFI State Implementation Grants for Integrated Community Systems for Child with Special Health Care Needs RFP – HRSA 2008)

PA Department of Health Project Intent: The Pennsylvania Department of Health's State Title V program housed in the Bureau of Family Health, provides and promotes family-centered, community-based, coordinated care for Children and Youth with Special Health Care Needs (CYSHCN). This State Implementation Grant project embodies a new vision for the way systems respond to the special health care needs of children, youth and their families. This vision requires that Pennsylvania medical, education and human service providers rethink and redesign the way services are delivered, coordinated and managed. It also focuses on the way service providers can more effectively coordinate and organize local resources to meet the transition needs of these individuals. The intent of this program is to rebuild infrastructure and systems at the local, regional and state level, one step at a time. The outcome sought is improvement in the well-being of CYSHCN and their families by providing tools, models, resources, capacity building opportunities and technical assistance supports to 1) improve the way children and families access and utilize programs and services in PA, and 2) assure the cultural competency of that service delivery. (excerpts taken from June, 2008 State Implementation Grant Proposal submitted to HRSA/MCHB)

Grant Leadership Partners:

Pennsylvania Department of Health, Pennsylvania Chapter of the American Academy of Pediatrics, The PEAL Center, The Pennsylvania Health Law Project

State Implementation Grant Mission: To create sustainable improvements in systems serving children and youth with special health care needs in PA through family-professional partnerships that embody family-centered care and culturally competent principles including: youth leaders, parents, community groups, health care professionals, and government agencies.

Specific Goals and Priority Areas:

Goal 1: Strengthen system capacity by integrating local, regional and statewide parent/professional, community, provider and systems partnerships to advocate for the needs of children and youth with special health care needs (CYSHCN).

Objective 1: Identify and nurture parent/professional partnerships that focus on CYSHCN at the local, regional and statewide levels. Project will foster skill building among all stakeholders through training for all partners.

Objective 2: Identify, utilizing input from all partners, current service capacity and availability by creating a database (using geo-mapping) to display what services exist now. As a result, identify services needed but not available due to eligibility criteria, regional disparities or limited funding.

Objective 3: Draft recommended policy changes at the local, regional and state level and advocate for a more seamless family centered service system for CYSHCN via the Title V CSHCN Stakeholder Group and other child advocacy organizations.

Goal 2: Ensure all children in PA receive comprehensive, coordinated care in a medical home by expanding provider capacity for CYSHCN, with an emphasis on the underserved.

Objective 1: Build on the existing EPIC IC -PA Medical Home program by engaging Federally Qualified Health Centers (FQHC), FQHC look-alikes and Rural Health Centers (RHC) participation and encourage all medical home practices to serve on regional parent/professional partnerships.

Objective 2: Continue work with State Office of Medical Assistance Programs on health care utilization analyses/reimbursement, quality improvement, and maintenance of certification, National Committee on Quality Assurance/Patient Centered Medical Home & pay for performance initiatives to achieve sustainability.

Objective 3: Work with parent/professional partners through regional work groups/learning collaboratives to foster early family links to services including: services for CYSHCN, infants identified via newborn screening and improving specialist-primary care provider communication.

Goal 3: Integrate the educational, medical wellness and community systems to ensure that YSHCNs make successful transitions to all aspects of adult life.

Objective 1: Develop a model integrating medical/education transition planning via a learning collaborative including: Dept. of Education, Bureau of Special Education-Transition, Healthy and Ready to Work (HRTW), Dept of Public Welfare – Office of Medical Assistance Programs, Long Term Living and Disabilities Programs, Medical Home Practices, Elks/School Nurses, YSCHN, families, and employers.

Objective 2: Create an easy access for youth, parents and health care providers to transition information and services that provides equitable access to information without having to go through a gatekeeper.

Objective 3: Collaborate with the PA Youth Leadership Network to expand the cadre of leaders so youth leaders could be identified in each region to work with government agencies, medical home practices, stakeholders and community partners.