

## **HEALTHY AND READY TO WORK (HRTW) SERVICES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS (CYSHN)**

Project Title: Youth-Centered Model for Transition of Arizona YSHN: Healthy and Ready to Work  
Project Number: CFDA # 93.110D  
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Project Period: 4 years  
From: 6/1/01 to 5/31/05

### **ABSTRACT**

#### **Organizational Setting:**

The program is directed by Arizona State University, PIs, Tanis Bryan, PhD and Karen Burstein, PhD, in collaboration with Title V (AZ Dept. of Health Services Office for CSHN--ADHS/OCSHN/CRS), Susan Burke, EdD, Director and physicians Harold ReKate, MD and Theodore Tarby, MD, PhD and community based Phoenix Pediatrics, David Hirsch, MD, FAAP and Kevin Berger, MD, FAAP.

#### **Purpose:**

The proposed project develops, implements and evaluates a transition model that addresses core issues identified by the National Agenda, "Achieving and Measuring Success for Children with Special Health Care Needs by 2010"

- 1) All youth with special health care needs (YSHN) receive services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.
- 2) Families *and* YSHN participate in decision-making at all levels and are satisfied with the services they receive.

#### **Challenge:**

Although legislation is in place, YSHN are less likely than non-disabled peers to graduate from high school, attend college, work in competitive employment or live independently. Many middle-aged adults who grew up with chronic health conditions are still treated by pediatricians; many seek health services only in emergencies. Adult health issues, e.g., reproductive health, adult onset diabetes, cancer, are being neglected. At the same time, however, adult providers do not feel adequately prepared to provide YSHN services, and are concerned about the time and resources necessary to provide services.

#### **Goals:**

The proposed project meets the highest priority of the MCHB to integrate personal health care and public and private health services to establish a replicable and sustainable community system of comprehensive services, which is family-centered, culturally competent and integrated with education, social services, mental health and family support programs. The model meets the HP 2010 objective that all YSHN receive the services necessary to make appropriate transitions to all aspects of adult life.

**Objectives:**

1. Build capacity of adult health care provider system to receive transitioning YSHN by a) Establishing a collaborative network of pediatric and adult health care providers in the Phoenix metropolitan area, b) Training adult providers on issues related to transition, c) Increasing interagency linkages to improve access to services.
2. Build YSHN capacity for self-determination using Participatory Action Research (PAR) for identification of strategies for long-term health and disability management, vocational and educational choices, and peer and family supports. When feasible, YSHN use technology (e.g., video, Web, PDAs, wireless communication) as a means of a) monitoring their health status, b) communicating with providers and peers, and c) participating in PAR
3. Build family capacity to address their concerns regarding YSHN transition and increasing independence by having groups of parents identify problem solutions through PAR.

**Methodology:**

(1) A network of 20 providers, including community based pediatricians, Title V providers, sub specialists, and adult primary care providers in the Phoenix metropolitan area form a Transition Network to collaborate on: (a) training adult providers on YSHN and developing adult Medical Homes, (b) training YSHN in personal health care management using a medical teaching exam, and the Youth Individual Profile and Plan (YIP-P), (c) developing family support for transition and independence, and (d) developing cross disciplinary Systematic Transition Plans.

(2) YSHN being transitioned from Phoenix Pediatrics and Title V CRS clinics into adult care acquire the self-determination skills necessary for healthy physical and mental life styles through: a) engagement on teams using PAR to identify solutions to problems, participation in their medical exams, and identification of community resources needed for setting and achieving goals. YSHN use the YIP-P, a comprehensive durable medical record that includes past and present health status, PAR data, and Transition Plans. Further, when feasible, YSHN acquire skills in using personal data assistants (PDA's) and electronic transmission of data for record keeping and communication with providers, peers, and the Internet.

(3) The YSHN's families also do PAR to identify solutions related to their concerns about YSHN's assuming personal responsibility for health care and making the transition to adult health care, as well as coping with adolescent issues related to sexuality, education, housing, work and finances.

(4) Project faculty use outcome data to evaluate the impact of program participation on YSHN, families, and providers; and produce training modules based on components shown necessary for successful transition. Products are disseminated nationwide to professional and family organizations concerned with YSHN through Raising Special Kids, Family Voices and Exceptional Parent magazine and Web sites. Because youth and families from diverse cultural, ethnic, socioeconomic, urban, suburban and rural backgrounds participate in developing and testing the model, the modules are culturally competent and family and youth -centered.

**Evaluation:**

The evaluation assesses 1) Input data (e.g., critical stakeholders participate in the identification of issues and the design of solutions), 2) Implementation data (i.e., project goals are met in a timely fashion, and 3) Impact data (e.g., prospective, longitudinal tracking of program effects on YSHN's transition to adult health, education and vocation opportunities; growth and stability of transition network and interagency collaboration, and consumer and provider satisfaction).

**Text of Annotations:**

In the Youth-Centered Model for Transition of Arizona YSHN a network of health care providers and critical stakeholders develop protocols for (a) training adult health care and ancillary service providers in the care of YSHN and the Medical Home, (b) training YSHN in personal health care and counseling necessary for making educated choices using the Youth Individual Profile and Plan (YIP-P), (c) and (c) supporting families in their youth's quest for independence. YSHN in transition and their families engage in PAR to identify barriers and test solutions to adopting healthy adult life styles, pursuing continuing education and employment. The evaluation examines program impact on youth, families and providers across 4-years. The program produces a series of training modules for widespread dissemination.

**Key Words:**

Children and youth with special health needs, YSHN, Physician training, YSHN training, Participatory Action Research, PAR, Family support, Youth Individual Profile and Plan (YIP-P), Systematic Transition Plan, STP.