ISSUE BRIEF 08

Optimizing Resources to Ensure Successful Transition to Adulthood for CYSHCN

INTRODUCTION

All children deserve a future, to grow up and to be as independent as possible in their lives and in their communities. For many children and youth with special health care needs (CYSHCN), this will mean employment for many, improved recreational and social opportunities for others within their own communities, and for ALL, an improved or sustained health status as they age into and access adult health care delivery. When MCHB began the Healthy & Ready to Work initiative in 1996, the terminology youth with special health care needs (YSHCN) and children and youth with special health care needs (CYSHCN) has been used. Since that time, MCHB has funded 14 states with Healthy & Ready to Work grants and one national technical assistance center to pave the way for all states to mount implementation efforts that target transition.

So what's health got to do with the transition to adulthood for YSHCN? Everything! Health impacts all aspects of life and success in the classroom, within the community, and on the job requires that young people with special health care needs stay healthy. To stay healthy, young people need an understanding of their own health and to participate in their health care decisions. For the first time, a generation of American YSHCN have survived beyond their diagnosis/prognosis. But due of poorly managed health problems and low expectations, many are unable to maintain placement in higher education, sustain employment, or live independently. Youth with special health care needs are neither CHILDREN nor ADULTS. Their issues and concerns are similar, but different from both. This pivotal time called youth should be a time in which the total environment supports the child in becoming an adult. This support should encourage the aspirations and expectations that lead to productive adulthood. On the other hand, if these supports are absent, this period can be ingrain feelings and behaviors of self-doubt, confusion, and poor initiative.

Preliminary Findings

Discussions at the federal, state and community levels have identified some common findings and strategies that underscore why states can no longer wait to address transition to adulthood for CYSHCN.

Transition to adulthood for CYSHCN is an on-going process, rather than a discrete event to be checked off on a care coordination checklist.

- Many CYSHCN have little or no experience managing their own health care, making medical appointments, or even understanding and discussing the specifics of their medical conditions.
- Many youth want education and employment opportunities, but think that adults either have low expectations of their abilities and future prospects or present barriers to attaining a degree of independence that would be considered normal for a young adult without special health care needs.
- In some cases families are unaware of the existence of programs and resources that could help.
- Pediatric and adult health care professionals often do not communicate with one another, much less collaborate, to achieve successful transitions of care from one to the other as children mature.
- The need for collaboration between state health care systems and the education, rehabilitation or insurance systems is beginning to gain visibility and momentum related to planning and facilitating transition to adulthood.

STATE AND COMMUNITY STRATEGIES

Transition efforts are now coming up on the radar of state CSYCN programs and their partners. Supporting the transition of CYSHCN from Title V CSHCN agencies to adult health care and services is not just a good idea—it's an integral part of everyone's job! Successful transition to adulthood relates to all the CSHCN performance measures and is the outcome of all services for CSHCN and should answer the question, "Did what we do matter?" While relatively new, many states are harnessing the energy of youth and their families to help create meaningful policies and practices that support the successful transition to adulthood. One indicator of states' interest and commitment to addressing transition is the fact that 15 out of the currently-funded 33 State Incentive Awards from the Champions for Progress Center target transition to adulthood.

• Before they reinvent the wheel in implementing transition activities, states should begin by partnering family and youth leadership organizations. For example, national youth leadership groups, such as KASA—Kids As Self-Advocates (www.fvkasa.org) and the National Youth Leadership Network (www.nyln.org), provide a network of skilled youth leaders who are involved in policy shaping and decision-making. Parent Training Information Centers (www.taalliance.org) and Family Voices Coordinators (www.familyvoices.org) also develop leadership abilities and help families of CSHCN with their specific concerns.

• The recognition of the importance and challenges of youth transition is being recognized by other national agencies and programs. Youth stakeholder groups should attempt to partner with and identify advocates within departments of education, particularly special education; post-secondary education; vocational rehabilitation; and state chapters of the American Academy of Pediatrics, Academy of Family Practice, and Internal Medicine.

• Mentoring for youth is offered via a number of organizations and websites (www.dmd-aapd.org)as well as through state institutions of higher learning, such as in Florida (www.thetransitioncenter.org).

• In addition to hiring parents to work with local CSHCN clinics, some states, such as Arizona, employ youth who serve as liaisons that work directly with youth and their parents as well as in an advisory capacity (www.azdhs.gov/phs/ocshcn/education_advocacy/parent_youth_advisors_az.htm).

• In order to inform and harness the energy of youth, states such as Wisconsin, Arizona, Alabama, Nevada, and New Mexico, sponsor statewide Youth Conferences designed by youth for youth. Maryland's conference addressed physical and cognitive disabilities as well as diverse cultural and ethnic issues.

• Youth advisory committees in states such as Colorado, Florida, Maine, and Tennessee, give a unique perspective to program planning and build confidence and competence in the participating youth. When program planning involves youth, they are viewed as more than simply patients and their voices and opinions are valued.

• Person-centered planning and mentoring programs are offered for youth in collaboration with condition-specific agencies, such as the Spina Bifida Association, United Cerebral Palsy, University Centers for Excellence in Developmental Disabilities (UCEDD), youth leadership organizations such as Kids as Self Advocates—KASA (www.fvkasa.org), National Youth Leadership Network (www.nyln.org), and others.

• State and federal programs fund agencies in all states to fund and provide access to independent living training, transportation, and assistive technology services. Collaboration and referral helps these agencies meet their missions and can be cost-neutral with time rearrangement for the Title V agency staff.

DISCUSSION QUESTIONS FOR COMMUNITY-BASED TEAMS

At a series of Multi-State Meetings hosted by the Champions for Progress Center in 2004, state CSHCN staff, parent representatives, and other partners discussed the topic of Building State & Community Teams. The questions can be used by interagency community teams and councils in order to share information and to build relationships.

1. How is our community and state increasing the awareness and knowledge of families and youth at the community level about transition to adulthood?

2. What efforts do we have in our community and state to ensure medical homes for youth with special health needs that are entering their 20's?

3. Does our state have mechanisms for collaborating with culturally and linguistically diverse youth and/or their families in order to better understand and facilitate their transition needs and preferences?

4. What are the greatest accomplishments in our community and state that optimize resources to ensure successful transition to adult life?

5. What are the greatest challenges in our community and state that optimize resources to ensure successful transition to adult life?

Useful Links and Resources:

Healthy & Ready to Work: www.hrtw.org **KY Commission for CSHCN:** http://chs.ky.gov/commissionkids
University of Washington Health Transition Project: http://depts.washington.edu/healthtr
Wisconsin Youth Conference: www.waisman.wisc.edu/hrtw/descr.html
Family Voices - Kids As Self-Advocates (KASA): www.fvkasa.org
Maine Youth Speak: www.umaine.edu/cci/service/maineworks/activities.htm
Florida Youth: http://www.cms-kids.com/CMSNTransition.htm
National Center on Secondary Education and Transition: www.ncset.org/default.asp
National Collaborative on Workforce & Disability for Youth: www.ncwd-youth.info

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