PA Consortium for CYSHCN
Background Brief
Transition

This background brief presents an overview of the status of **transition to adulthood services** for children and youth with special health care needs in Pennsylvania.

The federal Maternal and Child Health Bureau identified six core outcomes as critical indicators of success in implementing community-based systems of services for all CYSHCN in accordance with Healthy People 2010 and the President's New Freedom Initiative. This background brief relates to Core Outcome #6:

Youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence.

Background

Youth who have special health, emotional, or social needs face significant challenges as they manage the transition from adolescence to adult roles and responsibilities. It is not surprising that affected youth are more likely to experience gaps in health care, and educational and vocational experiences which lead to increased rates of unemployment and mental health problems. (HP 2010) This white paper will provide background and recent research on the status of transitioning youth, followed by questions for discussion.

Government Interest in Transition Issues

In 1989, the Surgeon General sponsored a conference titled ''Growing Up and Getting Medical Care: Youth with Special Healthcare Needs." Since then there has been increased interest in the transition process within the medical, educational, social service, and government communities. Key achievements have been the passage of the Individuals with Disabilities Act (IDEA), which defines transition services as coordinated set of activities for a child with a disability that:

1. Are designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.
2. Is based on the individual child's needs, taking into account the child's strengths, preferences and interests.
3. Includes instruction, related services, community experiences, and the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation. (United States Department of Education, Individuals with Disabilities Education Act: Part B. Section 602(34). Available at: http://idea.ed.gov/explore/search; 2004.)

The Maternal and Child Health Bureau, also in 2004, described Transition as the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals to ensure successful transition to the adult health care system, work, independence, and inclusion in community life. (MCHB: McPherson, Weissman, Strickland, Van Dyck, and Newacheck 2004.)

PA Consortium for CYSHCN
Background Brief
Transition

Evidence of disparity

There is a rapidly growing evidence base that disparities exist between youth with special needs and the general population regarding access to continuous relationships with adult-oriented health care providers, continuity of adequate health insurance, and employment.

- In a statewide (KY) survey of young adults who received Title V services and/or 'aged out' of Pediatric services, Blomquist and colleagues found that nearly a third were uninsured, and 44% unemployed. (Blomquist et al. Orthopedic Nursing 25(3), 2006.)
- According to a 1994 survey commissioned by the National Organization on Disability, the vast majority of (79%) of jobless adults with a disability say they would like to work. (NOD/Harris survey 1994.)
- Young adults are twice as likely as children and older adults to be uninsured. In fact, 19-29 year olds account for 40% of the growth in uninsured populations since 2000, although they represent only 17% of the population. (Commonwealth fund 2006, www.cmwf.org/usr_doc/Collins_riteof passage2006_649_ib.pdf)
- In a national survey of nearly 50,000 individuals with chronic health conditions aged 13 to 32, Adams et al reported the lowest insurance rates in the 23-24 year old group. Latino/a respondents where at particular increased risk of being uninsured at every age level. (Adams et al, Pediatrics 119(5) 5/07.)
- In a longitudinal study of 5170 young adults with and without physical disability, Callahan and colleagues reported that individuals with disabilities were more likely to have incomes below 200% of the Federal Poverty Level, more likely not to be enrolled in school or vocational program, and more likely not to have a paying job. (Callahan and Cooper, Pediatrics 119(6) 12/07.)
- Lotstein and colleagues reported that in a sample of 21 to 24-year old individuals who received Title V services as youngsters, one in four had no usual source of health care, and nearly two in five experienced a gap in insurance and health care since age 21. In this sample, 65% of participants experienced one or more adverse transition event. Less than one in four of respondents possessed employer-based insurance. (Lotstein et al. Journal of Adolescent Health 43 (23-9); 2007)

Transitions from Pediatric to Adult Care

Focusing on the transition from pediatric to adult-oriented systems of health care, there is increasing evidence that significant gaps exist between the abilities of pediatricians and adult-oriented providers regarding the needs and abilities of young adult survivors of congenital or chronic childhood disease.

- Less than one in five general internists reported feeling comfortable being a primary care provider for adults with Cystic Fibrosis. (Okumura et al; Journal of General Internal Medicine Aug 2008.)
- Families and youth who are transitioning or have transitioned to adult providers reported feeling that adult-oriented providers lack training, up-to-date knowledge, and interest in their illness. (Reiss et al; Pediatrics 115, 2005.)
- A survey of general internists conducted from 2001-4 revealed a need for improved training and exposure to patients with congenital and childhood-onset conditions. They also reported a lack of trained sub-specialists, and a need for improved systems of financial support for affected young adults. (Peter et al; Pediatrics 123(2), 2009.)

PA Consortium for CYSHCN
Background Brief
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The CDC's National Survey of Children with Special Health Care Needs provides state-by-state data regarding progress toward implementing community-based service systems. Data from the 2005-06 survey reveals the following data regarding Pennsylvania:

- Did the family receive effective care coordination services? 60.4% (National average 59.2%)
- Does the individual have insurance that usually or always meets the child's needs? 87.2% (National average 87.3%)
- Has the family received services and information to achieve successful transition to adult services- 46.0% (National average 41.2%)

Questions for Discussion

1. What transition services are available, and what is the capacity to answer unmet needs?
2. Where do people go for support/education/resources on transitional issues?
3. Is access to a medical home for CYSHCN ages 12-17 years available to everyone?
4. How can access to continuous and comprehensive health insurance up until the time an individual with special needs can achieve employer-based insurance be improved?
5. How can opportunities to develop work skills and technical training be integrated with health-related transition services?
6. What strategies will result in stimulating career opportunities for adults with special needs?
7. How can coordination of transition services offered by the Commonwealth, specifically in health, social/welfare programs, and education, be improved?
8. What opportunities can develop to enhance training of adult-oriented health care providers (PCPs and specialists) on congenital and other childhood-onset diseases?
9. Is it feasible to improve skill sets in family-centered care within adult-oriented health care systems (as opposed to individual patient centered or physician centered care)?
10. What needs to be accomplished at the local, state, and federal levels to improve access and coordination of transition services?

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