

Transitioning patients with pediatric disease to adulthood

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Growing pains can mean one thing for a typical adolescent and quite another to an older teen with cerebral palsy attempting independence in an adult world. A unique program, the Indiana University School of Medicine Center for Youth and Adults with Conditions of Childhood (CYACC) is helping these youths spread their wings and live more independently.

IU pediatricians at Riley Hospital for Children have been at the forefront of innovative care for patients, including advances that over the past three decades have created new challenges for patients with special needs and their caregivers. Now, Riley physicians are leading the way to providing a solution.

CYACC provides interdisciplinary consultation in a health-care setting to specifically address transition and adult life issues regardless of the youth or adult's diagnosis.

“Twenty to 30 years ago it was not unusual for children with serious congenital or developmental conditions to die before reaching adult life,” said Mary Ciccarelli, M.D., an assistant professor of clinical medicine and pediatrics at the IU School of Medicine and medical director of CYACC. “Today, the life expectancy of many of these children reaches well into adulthood yet there are few programs available to help them transition to independent lives with both the best health status and the fullest participation in their communities.”

Nationally, there are only a handful of programs that are beginning to address the need, Dr. Ciccarelli said. It is estimated that 4,000 Indiana youth with special health-care needs experience transition into adult life each year.

CYACC patients, who are between the ages of 11 and 22 years, are seen at the Wishard Primary Care Center on the IU Medical Center campus. Frequent diagnoses of patients served by the CYACC team are cerebral palsy, Down syndrome, autism, diabetes, rheumatologic disorders and spina bifida. Resources in many specialties and disciplines are involved to successfully integrating youth with chronic conditions into the adult world.

Psychosocial, educational, vocational and medical needs of the adolescents are addressed by the interdisciplinary team of physicians, nurses, social workers and community organization liaisons. Health-care coverage options and applications are made available. Family support and education are provided. While increasing numbers of community programs provide resources or accommodations for those with disabilities, many families are not aware of these opportunities in their communities. Collaboration is tailored for each individual with schools, employers, and agencies that can provide services for youth and their families.

Coordination of medical care also is one of the key issues the team addresses. With more than 300 unusual chronic conditions with onset in childhood, adult practitioners often have never provided care for individuals with the majority of these conditions. Pediatric doctors are trained to care for youth with childhood diseases but are not routinely familiar with addressing issues such as reproduction and other health issues common in adult life.

The team approach provides hands-on learning opportunities for IU

School of Medicine physician residents in training. By involving the young physicians, CYACC extends its mission; these residents will take with them an awareness of the comprehensive medical, social and educational needs of this group of patients as they begin their careers in Indiana or elsewhere.

Source: Indiana University

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