Beyond Childhood: Helping Patients with Special Needs

Florida HATS offers resources to help disabled patients who have aged out of pediatric care.

By Janet Hess, M.P.H., and David Wood, M.D., M.P.H.
What happens to young adults with disabilities or chronic health problems when they age-out of pediatric health care? The large number of young people with special health care needs moving from pediatric to adult health care is a relatively new phenomenon.

Thanks to medical care advances, we’ve seen dramatic increases in survival rates among children with special health care needs. Yet, we do not have a system that adequately supports them as they become adults. Some of the problems they face are finding adult physicians who are qualified and willing to provide care, difficulty accessing affordable health insurance, and inadequate preparation for health care self-management. Young people who don’t receive age-appropriate and preventive care are more likely to experience disease complications, increased emergency room visits and hospitalizations, and secondary disabling conditions — all factors that affect their quality of life and ability to work.

FloridaHATS (Health and Transition Services) was established in 2009 in response to legislation mandating a statewide task force to assess health care transition issues. Its main goal is to provide leadership in bringing together consumers and service providers to address the complex issues associated with transitions for all youth and young adults with special health care needs.

While the program is positioned within Children’s Medical Services (CMS), it is a collaborative initiative involving partners and agencies throughout the state, including the Florida Developmental Disabilities Council Inc. Our recently formed Medical Advisory Committee (MAC), which includes pediatric and adult medical providers throughout the state, works with the Florida Pediatric Society and Florida Medical Association on several advocacy and training activities.
In addition to its work in financing, education, and training, FloridaHATS provides technical assistance in building local service networks that span pediatric and adult systems. During the past year, public-private coalitions were organized in three pilot regions: Tampa-Hillsborough County, the Panhandle, and Jacksonville-Duval County. A network of health care experts provides guidance on identifying best practices, establishing quality of care guidelines, and developing model programs, such as the nationally recognized JaxHATS Medical Home program for transitioning young adults in Jacksonville.

The FloridaHATS website, www.FloridaHATS.org, provides a rich repository of resources for youth, families, and providers. Here are a few items you will find on our site:

- Florida Health Services Directory for Young Adults is a web-based directory that is searchable by community, county, keyword, and/or service category. If you provide health-related services for adults with disabilities or chronic health conditions anywhere in Florida, please make sure you are listed in the directory. Just complete the online submission form to add or update a listing.

- Just the Facts: The 411 on Health Insurance for Young Adults Ages 18-30 in Florida helps young adults with and without disabilities decide which health care coverage options might work best for them. Using a matrix design, it lists private and public financing options available in Florida, key eligibility requirements for each, considerations in choosing a plan, how to apply, potential out-of-pocket costs, monthly premiums, the good and not-so-good points about each plan, state and federal laws, and resources to learn more. The guide is updated regularly to reflect state and federal guidelines, and is available online in Spanish and Creole.
• Health Care Transition Training Program for Professionals is an online training curriculum that provides up to four free CME/CE credits to physicians, nurses, psychologists, dentists, social workers, nutritionists, and mental health counselors. The training module is offered through the Gulfcoast North Area Health Education Center at www.aheceducation.com. In addition, the MAC is planning a series of training events at conferences and Grand Rounds in the coming months.

• There are many of downloadable tools and forms to help facilitate smooth, uninterrupted care for patients with chronic-complex health conditions. These resources include developmental check lists and care plans, medical summary forms, information on decision-making and guardianship, guidance on integrating health care transition activities into school-based Individualized Education Plans (IEPs) and classroom instruction, and much more.

We invite you to learn more about FloridaHATS by visiting www.FloridaHATS.org or by contacting Project Director Janet Hess, M.P.H., at (813) 259-8604 or jhess@health.usf.edu, or CMS Medical Consultant David Wood, M.D., M.P.H., at (904) 244-9233 or david.wood@jax.ufl.edu.

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