Adulting is Especially Difficult for Youth with Special Health Care Needs

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As we can all attest to, becoming an adult is difficult. As youth become adults, they are expected to take on increasing responsibility in all aspects of their lives, including health care. This increased responsibility is accompanied by having to make decisions about what do to after high school graduation – like finding a job – and how to live independently, all while balancing various changing psychosocial factors including where to live and what health insurance to sign up for. This phase of life is even harder for youth who have special health care needs.

There are approximately 4.3 million adolescents with special health care needs in the United States, accounting for nearly one in five adolescents in our country. Special health care needs range from mental health problems to sickle cell disease to cerebral palsy. Although the experiences of these adolescents differ, they often share a need for additional support services – like help managing a range of medical appointments or access to special therapies – to assist them in achieving their highest potential in adulthood. These challenges can be heightened if they also have an intellectual disability.

Here at CHOP, we have developed innovative programs and tools to support these youths. One example is the Multidisciplinary Intervention Navigation Team (MINT), a clinical service devoted to improving the quality and safety of transfers from pediatric to adult health care systems, primarily Penn Medicine. Over the last two years, the MINT team has worked with over 80 patients with multiple chronic conditions or intellectual/developmental disabilities in need of enhanced transition services. In addition to preparing youth for medical transition, MINT utilizes various support staff to assist in other areas of the transition process. For example, MINT's Youth Community Health Worker (YCHW) supports youth in developing self-care and self-advocacy skills.

Recently, the YCHW worked with Jessica*, a 21-year-old CHOP patient with sickle cell disease and a challenging psychosocial background. Since Jessica was 18, her mom has not been involved in her medical care. She enrolled in community college, but had to withdraw because of her unstable medical condition. Jessica has a full-time job, but often presents at the emergency department for routine care instead of going to her primary care provider.

During a one-on-one visit with the YCHW, Jessica explained how making phone calls causes her anxiety, expressed confusion about deciding between the insurance plans offered at her job, and indicated that her goal is to return to college. Together, Jessica and the YCHW identified two short-term goals and one long-term goal. The first short-term goal was to practice making polite and effective phone calls to providers and pharmacies using a script from the YCHW. The second short-term goal was to sign up for the online portals offered by her pharmacy, health care providers and insurance carrier. Together, Jessica and the YCHW signed up for and explored each portal and read the covered benefits for the insurance plans she was considering.

Jessica's long-term goal was to return to community college within the next year. As a first step, Jessica and the YCHW made a timeline during their time together at her appointment that covered the steps along the way to reaching her goal, including: improving her adherence to her health care plan, applying for FMLA, applying for financial aid and applying to return to college.

This innovative work is being done at institutions like ours across the country. Yet, significant barriers remain to transitioning this population to adult health care systems and adult life. Our new Evidence to Action brief, "Transitioning to Adult Care: Supporting Youth with Special Health Care Needs," synthesizes new research identifying specific barriers and describes opportunities to facilitate high-quality transition for these adolescents. In it, we propose:

- that providers and practices should begin early in preparing adolescents to take on a larger role in their health care,
- health care systems should work together to create trusting relationships and educate each other on how to care to complex patients, and
- policymakers should incentivize providers for the time it takes to coordinate care for these patients.

Without changes to our current transition practices, patients like Jessica would continue to flounder in the space between pediatric and adult life. Fortunately, her experience with MINT is evidence that health care systems across the country can make a significant difference in the lives of all adolescents with special health care needs.

*Name has been changed to protect patient privacy

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