

## Insights

# Preparing Children with Special Healthcare Needs for Transition of Care

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Health care transition is the

process of changing from a pediatric to an adult model of health care. There are significant differences between adult and pediatric health care model, which can make transitioning from pediatric to adult care challenging for any young person, but those challenges are often amplified for children with special healthcare needs. The majority of U.S. youth are not receiving transition preparation, according to the [2020-2021 National Survey of Children's Health](#), a nationally representative survey of parents. New estimates of transition preparation for youth (ages 12 through 17), reveal that 84% of youth with special healthcare needs and 80% of youth without special needs do not meet the national health care transition (HCT) performance measure.

The Florida Children's Medical Services Learning Action Network (LAN), led by NICHQ in partnership with the Florida Department of Health, supports seven specific Statewide Networks for Access and Quality (SNAQ) and one Regional Network for Access and Quality (RNAQ) that are dedicated to improving the quality and access to care for children and youth with special healthcare needs. NICHQ facilitates LAN goals through teaching and supporting the application

of the Model for Improvement to increase quality improvement capacity of participating teams.

Chloe Provenza, 18, and Parker Lentini, 24, have been managing complex medical conditions for most of their lives. They recently joined a learning session for the Florida Children's Medical Services Learning Action Network to share their experiences and provide insight to healthcare teams with quality improvement projects centered around transition of care. Below, we share a summary of the strategies.

## **Involve patients in their care**

It's important to involve adolescent patients in their care, including discussions about transition. Although parents and caregivers are important members of a young person's care team, they are not the patient. Ensure young people with special health needs understand insurance continuity and are equipped for the responsibility of managing their care after transferring to an adult provider. Education and counseling of patients and families works to enhance their active participation in their own care including informed decision making.

"I've always taken on my disease myself, and my mom has been in a side role," Lentini said. "I've had allergies since I was a baby. When I was diagnosed, I wanted to know everything about my disease. I thought it was like my grandma's arthritis, but Systemic Juvenile Arthritis impacts your joints and internal organs. It's been a journey I didn't even imagine, but I've been involved since the beginning."

## **Prepare patients for transition with advanced notice**

"When I turned 16, at my 15-year-old appointment, they told me I had to find a new pediatrician who would work with me until I was 18, then I'd have to transition again to a new one when I became an adult," Provenza said. "It was a disappointing and scary experience."

Many patients with special health needs spend years with the same team of trusted providers and specialists who are familiar with the intricacies of their needs. However, there are a variety of reasons a patient may need to find a new provider, and some can be unexpected. When possible, provide patients with advanced notice to ensure they have time to ask questions and voice their concerns.

According to an article published in the National Library of Medicine, "[Transitions From Pediatric to Adult Care](#)," the role of pediatricians in the process of transition of care is especially important since they are in frequent contact with the adolescents and build a close relationship with their families. The process should begin with the development of a transition policy and its dissemination to all families, to ensure they can understand that transition planning will be part of chronic care management.

## **Connect patients with new providers**

Providing adolescent patients and their caregivers recommendations for future health services, and working with them in advance on a transition plan can lead to better outcomes as they begin accessing adult health care.

Providers are an invaluable resource to help ensure health care services are available in an uninterrupted manner as a person moves from adolescence to adulthood. The role of pediatricians in the process of transition of care is especially important, since they are in frequent contact with adolescents and often build close relationships with their families. Developing and disseminating a transition policy should be standard for providers working with youth with special health needs to ensure they can understand that transition planning will be part of chronic care management.

"I've had specialists in the past work with me and tell me in advance that I'd have to transition my care in the next few months," Lentini explained. "They assisted by offering follow-up support if I was unhappy with my new provider so that I could be placed with a better fit. That made it a much less overwhelming experience since I wasn't scrambling."

Looking for more resources that support transitions in care? Read [4 Strategies for Transitioning from Pediatric to Adult Care for People Living with Sickle Cell Disease](#) and [Improving Transitions in Care Saves Lives](#).