Imagine the teen who survives premature birth and a subsequent stroke, told by her parents that she's a "miracle baby" — alive today through the grace of God and medical technology. Year after year, advances in surgical procedures and new medications for her cerebral palsy and seizure disorder offer her hope for a long, happy and productive life. Trouble is, the adult medical system is totally unprepared to provide the care she needs.

Each year in Florida, almost 50,000 youth with chronic health conditions or disabilities become adults. For most, it's like entering a black hole. Some have problems getting adequate insurance coverage after they age out of their childhood plan. They're usually required to leave their pediatrician at age 18 or 21, and many struggle to find physicians in the adult system who are qualified and willing to treat childhood conditions — or who take Medicaid or Medicare. And there is no systematic link between pediatric and adult health care systems to guide them through the transition.

Without ongoing care, these young people are likely to experience a disease crisis and end up in the emergency room. They could very well develop a secondary disabling condition. The cost is enormous, and not just in dollars and cents. Is it me, or does it seem ironic that a chronically ill child can be lovingly nurtured to adulthood, only to find there are few medical homes for miracle babies?
The problem is not unique to Florida, but this Florida Legislature has the opportunity to do something exceptional for our youth and young adults: begin building a bridge between the pediatric care they're getting and the adult services they so desperately need.

Senate Bill 566, introduced by Sen. Stephen Wise of Jacksonville, does just that. The legislation builds on an established system of care for eligible children with special health-care needs. Through Children's Medical Services (CMS), Florida's Title V program, kids receive comprehensive care coordination services up to age 21. SB 566 would extend the age cap to 26, allowing CMS to continue to assist these vulnerable young adults as they learn to navigate the adult health-care system.

Other provisions in the bill allow for consumer education about the health-care transition process and professional training to increase adult provider capacity. It designates a program within CMS, Florida Health and Transition Services (FloridaHATS) to help communities organize local service systems that link pediatric and adult health care for all youth and young adults. FloridaHATS has already partnered with advocates in Hillsborough County to form a community coalition — HillsboroughHATS — that is working on these very issues.

A couple of things SB 566 does not do: It does not provide payment for services — it's not an insurance plan — and it does not require a legislative budget appropriation. It simply extends CMS support and infrastructure to help close the health-care gap for Florida's chronically ill youth and young adults.

Isn't it time to help our miracle babies step into adulthood?

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