

Insights

Improving Transitions in Care Saves Lives



Until recently, sickle cell disease (SCD)—the

most common inherited blood disorder in the United States—was primarily considered a pediatric disease, with most children not surviving into adulthood. That's changed over the last two decades, thanks to innovative advancements in care and treatment. But even as these advancements have helped more children reach adulthood, health systems and providers have struggled to help children transition to adult care, resulting in high rates of complications and mortality for young adults.

Now, with data and measurement collection support from NICHQ, a [national initiative to improve sickle cell disease outcomes](#) is helping identify strategies to improve care during this high-risk period, which can ultimately have life-saving and life-changing benefits.

“Individuals with sickle cell disease develop multiple comorbidities during childhood—asthma, hip disease, neurocognitive challenges—and the complications from these can really be exacerbated if health systems don't support continuity of care,” explains Marsha Treadwell, PhD, who has published extensively on SCD transitions in care. “Look at the data: there is a dramatic increase in the number of deaths for those who are over nineteen when compared with children; and there is a big increase in emergency room visits, inpatient stays, and readmissions rates. There just isn't enough support during this high-risk period.”

Too few adult providers, coupled with limited resources for helping children and families manage their transition (e.g., connecting to a provider, understanding changes in health insurance, making appointments), mean that far too many young adults fall through the cracks. This can be especially problematic for those living in underserved communities [who already face significant challenges](#) in access to care and resources.

Equity and SCD: While sickle cell disease affects all racial and ethnic groups, it

[disproportionately impacts individuals](#) of African American/Black race and their families.

Supporting equitable access to care and addressing implicit bias in our health systems is critical.

Treadwell is the co-principal investigator for the Pacific Regional Coordinating Center (PSCRC), one of five regional coordinating centers (RCCs) that NICHQ is working with on the federal Sickle Cell Disease Treatment Demonstration Regional Collaborative Program ([SCDTRCP](#)), funded and managed by the Health Resources and Services Administration (HRSA). Below, she and Allison King, MD, the principal investigator for the Heartland Southwest RCC, share strategies their regions are leveraging to improve transitions from pediatric to adult care for adolescents and young adults with sickle cell disease.

Support transition readiness and planning in clinical settings:

Navigating the health care system as an adult takes a certain set of skills: connecting with a new provider, knowing how to fill a prescription, understanding the series of steps required to make an appointment, understanding your insurance coverage, to name a few. And these steps are notably more complicated when you're dealing with a chronic disease. Here, Treadwell and King share four tactics health professionals in their regions use to support transition readiness and planning in clinical settings:

1. ***Provide a readiness assessment or transition checklist:*** Evaluating the individual's readiness to navigate the health system helps providers and families address any barriers before the transition takes place. Assessments should evaluate readiness in terms of skill-sets (like making an appointment); knowledge about self-care and disease management (knowing their medical history, for example); and motivations and emotions (their confidence in their ability to transition). Treadwell and her team developed a sickle cell specific readiness assessment and several teams have added the American Society of Hematology's transition readiness assessment to individual electronic medical records. Similarly, King's team developed [a transition checklist](#) with nearly 100 questions that patients can complete in just ten minutes.
2. ***Proactively discuss a transition plan with families:*** The expectation of transition should never be unspoken, says Treadwell. The individual, their family, and their provider should engage in ongoing conversations about the eventual transfer to adult care and, together, develop a clear transition plan that details transition timing, provides necessary resources, and accounts for any barriers identified by the readiness assessment or transition checklist.
3. ***Help adolescents practice the skills they need:*** After patients complete the transition checklist, King's team provides tip sheets that help them practice any skills they may be missing, such as understanding their medical needs and what to do in case of an

emergency. Once they've practiced a skill, they can check it off the list and move on to fill another gap in their knowledge or skills, as needed.

4. **Prioritize an in-person handoff:** It's important for adolescents to meet their new provider before the actual date of transfer to adult care. This meeting provides an opportunity for young people and their families to discuss care details, ask questions, and establish a relationship with their new provider. Ideally, this meeting can happen at their new provider's office and include a tour of the office and new emergency and inpatient facilities, so patients can feel comfortable in their new environment. Michael Regier, LCSW, social worker with the PSCRC Colorado team, attends the first adult appointment with his young patients and may attend the second as well, depending on patients' comfort level with their new provider.

These tactics stem from six core elements to support the transition from pediatric to adult care, developed by Got Transition, a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. Elements include having a transition policy; developing a process for tracking and monitoring transition-age youth; assessing and using transition readiness assessments; planning for transition; transferring care; and completing transfers.

Partner with community-based organizations:

As children transition to adulthood and leave behind the medical home model of pediatrics, they need to feel capable of managing their own care. Along with assessing readiness in a clinical setting, partnering with community-based organizations has enormous potential for building their capacity. That's why the PSCRC is partnering with two different community-based organizations in California: The Sickle Cell Disease Foundation in Southern California and the Northern California Sickle Cell Community Advisory Council.

Both organizations have partnered with clinical sites to help empower adolescents and young adults as they transition to adult care. Successful strategies include setting up mock clinics where patients can meet their new provider and discuss self-care information, and hosting workshops where patients can learn about care-management, such as how to fill a prescription and talk to their insurance company, while meeting their new provider. The Southern California program also includes a focus on peer-mentoring, where young adults who have already transitioned to adult care mentor adolescents in the process of transitioning to adult care.

"Partnering with community programs has been a missing ingredient in sickle cell disease transition efforts," says Treadwell. "These partnerships provide another way to connect adolescents and young adults with the resources they need as they take on their own care, and help young people learn from and feel supported by their peers as well as their providers."

If possible, develop a transition clinic or have transition support staff:

In the Heartland Southwest region, all adolescents transition to a young adult clinic before transitioning to adult care. Their transition clinics, which see patients up to 26 years old, give young adults more time to learn the skills they need and feel confident in their abilities before moving to adult care. The Heartland Southwest region currently has two adolescent and young adult transition clinics, one at their main medical center in St. Louis, and a satellite clinic that

serves those further north.

In lieu of a designated transition clinic like the Heartland Southwest region offers, pediatric programs may need to continue to see patients into young adulthood, says Treadwell. As with a transition clinic, this extra time in pediatric care gives adolescents more time to learn, build skills, and gain confidence in their abilities. Both Treadwell and King have found that giving young adults extra support during the transition phase assures better health outcomes when they reach adult care.

“The sickle cell disease community has spent a lot of time looking at trends and trying to figure out why we’ve been able to reduce mortality in children with sickle cell disease but haven’t been able to address what drives the mortality rate up for young adults,” says King. “We know from other chronic diseases that it is really tough for adolescents—medical transition is just one facet of their transition to adulthood. That’s why focusing on education and building confidence is such an important piece; it builds the individual’s capacity for self-care.”

Looking for more resources that support transitions in care? The [Sickle Cell Disease Treatment Demonstration Program \(SCDTDP\) Compendium of Resources and Materials](#) (2018) and the [SCDTDP Model Protocol](#) (2017) include valuable resources and findings, including access to supportive videos, a curriculum for adolescents transitioning to adult care, and tip sheets for providers and patients.