

Insights

Sickle Cell Awareness Month: Transitioning to College, Equity Considerations, and Resource Sharing

by **Domonique Davis**, Communications & Digital Strategy Manager

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Domonique Davis: Hello, and welcome back to another edition of Before Birth & Beyond. In honor of Sickle Cell Awareness Month today I'm joined by NICHQ staff and project partners to discuss resources for people living with Sickle Cell Disease. First, we're sitting down with Kim Sprunck. Kim, can you please introduce yourself and share a little bit about what you do at NICHQ?

Kim Sprunck: Hi, thanks, Domonique, of course. I'm Kim Sprunck and I am the Director of Program Operations here at NICHQ. I am also the former Project Director for the Sickle Cell Disease Treatment and Demonstration Regional Collaborative Project and a current staff member for the Hemoglobinopathies National Coordinating Center Project.

Domonique Davis: Awesome. Thank you so much for joining us today, Kim. NICHQ has an extensive portfolio of projects related to sickle cell disease. Can you share some of the history of NICHQ's sickle cell work?

Kim Sprunck: Yeah, I'd be happy to. So NICHQ has a long history, a decade+, of working within the sickle cell disease space and really within the condition itself and how it intersects with newborn screening. So, we worked on a HRSA-funded sickle cell disease newborn screening program a number of years ago and that was really to link people with sickle cell disease and their families and caregivers to knowledgeable service providers. We also worked on New Steps 360, in terms of helping improve timelines of newborn screening to diagnosis. And that project was from 2015-18, and then recently, from 2021, as mentioned, I was the project director for the acronym SCDTDRCP, which was the regional collaborative project that I mentioned before. Currently, we are working with Abt Associates on the Hemoglobinopathies National Coordinating Center project.

Domonique Davis: So, a long history of sickle cell work and you have really been in the midst of it. How does NICHQ incorporate new developments in sickle cell disease research and treatment into some of these projects?

Kim Sprunck: NICHQ is really dedicated to making sure that we are working with those who are studying this and on the clinical side, as well as lived experts. And sometimes those are one in the same, but both those groups of people are essential for us to continue to work with and make sure that information is infused in all that we put out. Some of those things are the model protocol and compendium of tools and resources that we put together, which is a really important collection of information from those sources. Wonderfully, NICHQ's Communication and Digital Strategies Department collects a lot of information and pushes that out through newsletters and through our website, which is really exciting.

Domonique Davis: Final question for you. With NICHQ's commitment to equity, what are some equity considerations for NICHQ's sickle cell disease project?

Kim Sprunck: Well, for this, you really cannot talk about Sickle Cell Disease without talking about equity and the need for equity. The condition has been well researched and known for years, but the attention to it and the services has lagged. So, for us, it's really important to make sure that we are at the forefront of that discussion, as we work with community-based organizations, with those on the clinical side, with those in government, as we think about how to improve services for people living with the condition, as well as their caregivers, family members, and others who are really interested in ensuring that the care is improved.

Domonique Davis: Appreciate all you do and just want to give you space if there's anything else you want to share.

Kim Sprunck: Our commitment at NICHQ has been unwavering to this group of people and to those impacted by the condition. For those who are living with the condition as well as others, we will continue to be in this space to think about improving access to care, addressing equity issues, and improving the treatment and research around that, in the interest of making sure that all of that information is available.

Domonique Davis: Thank you so much, Kim.

Next, we'll hear from Madeline D'Onfro a project manager with our HNCC project. She'll share a little bit about college transition and some educational resources that are out there for people living with sickle cell disease and moving on to college. Madeline thanks for joining us.

Madeline D'Onfro: thanks, Domonique. Excited to be here.

Domonique Davis: Why is college transition such an important time for support needs and resources for people living with sickle cell disease?

Madeline D'Onfro: So for any young person, this is a really important time for support and resources, right? Whether they're transitioning to college or a full-time job or whatever next step might be right for them. It's a time when they're going to be establishing their independence from their nuclear family. They're going to be taking responsibility for their own needs and their life.

So, for a young person with special healthcare needs like Sickle Cell Disease, the responsibilities that they're taking on are going to be even more amplified on top of the normal transition that they face during this time period. They'll also be moving from pediatric healthcare, which often has more support, maybe your parents are involved– to adult healthcare, where they're really managing it on their own. As we all know, the healthcare system in our country can be really complicated and overwhelming regardless of your age, so for these young people, this time period requires them to navigate a really complex healthcare system. They need to practice self-advocacy. They need to deepen their understanding of their medical condition. All while growing into their self and working out who they are and what they want to do next with their lives. It's definitely a time when we need more support and resources.

Domonique Davis: Absolutely. Thank you, Madeline. It is tricky, like you mentioned, it's not just for folks with special healthcare needs, that adds onto it, right? It's a tricky time in general. Next question for you. Where can folks find resources to support transition? Know there has to be some out there.

Madeline D'Onfro: Yeah, fortunately, there are a number of really wonderful resources out there to support young people and their families during this time period. First, I want to highlight GOT transition as a great place to start for any young person with special healthcare needs as they transition care. There are resources there for young people, for their family members as well as for providers. It really goes through all the steps to think about as you move from one provider to another. And, I'd also suggest that listeners explore the 2021 Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program Compendium of Tools and Resources. It's a long name, but it can be found on NICHQ's website, and it is a compendium of all different types of resources, but there is a whole section on transition where we've linked to some really great tools and resources to help both the individual young person as well as their family through this time.

Domonique Davis: Well, that's great. We will be sure to include a link back to that compendium in our show notes. Thank you, Madeline. What are some basic steps students transitioning to college or just managing their adult care should take to prepare their medical care?

Madeline D'Onfro: Yeah, great question. And of course, it's hard to distill into just a few steps, but, I think I could think of kind of three big categories. So first, if possible, begin talking through transition with your pediatric care provider early, so even before you get to the space that you're going to be transitioning away from them. Start asking questions like, "How should I be preparing for this?" Work with them to put together a plan. Your provider should be able to help you get copies of your medical records. They'll be able to help you prepare a pain management plan, and they should also be able to help you seek out an adult care provider.

Working with them ahead of time will really, hopefully, set you up for success once it's actually time to choose to transition to that new provider.

Next, it's really important for young people to begin to practice advocating for themselves. And I want to acknowledge, of course, that young people with special healthcare needs are probably pretty good at this already. They've had to do this. They've been forced to learn how to do that quite early, unfortunately. Even so, it's good to practice making your own appointments, asking

for things that you need, and not being afraid to ask questions from your providers. We know that for young people who do decide to go to college, the schools will often look to the student to advocate for their selves, so in terms of both accessing medical care at college as well as seeking academic accommodations, you're going to be the one that has to handle all that, which can be a big transition for young people. Practice doing that. Making sure that you understand your medical illness and what your needs are and also make sure to seek support on campus. There are resources like the Office of Academic Accommodations and the Campus Accessibility Office that should be able to support you in this advocacy.

Then, finally, from many of the experts that we talked to, we heard about the importance of community. So, seeking out other young people and adults with sickle cell disease, asking them for advice and support, sharing your story with others, and just remembering that there's so much invaluable knowledge within community. The Sickle Cell Disease Association of America is a great resource. They have a database that can help you find a local agency or organization that works with sickle cell patients across the country, so try to reach out to organizations locally and help build the support of trusted providers and resources around you.

Domonique Davis: Next, we'll hear from TaLana Hughes, the Executive Director of the Sickle Cell Disease Association of Illinois. She'll share her background and knowledge about college transition. Thanks so much for joining us today. If you want to take a few moments to share with us a little bit about what you do with the association, we'd love to hear.

TaLana Hughes: Hi, and thank you for having me and inviting me again. I'm TaLana Hughes. I'm the Executive Director for the Sickle Cell Disease Association of Illinois. I do everything. So, I've been at the organization now for 20 years, and have been the executive director. about 15 years out of the 20, and I have a 20-year-old daughter who has Sickle Cell Disease. Here, we just do our best to change the landscape, to advocate, to increase awareness, just to really raise the bar when it comes to Sickle Cell Disease. And make sure that we support and extend the voices of our families that sometimes don't get heard or just sometimes are in situations where they don't necessarily have the support that is needed or even the empathy or compassion that is really needed to fully care for individuals with Sickle Cell Disease.

Domonique Davis: You all are doing really important work and we so appreciate you. With September being Sickle Cell Disease Awareness Month, We know y'all are in the thicket of putting on some really important events. They have an upcoming walk/run. So, TaLana, we wish you all the luck with your walk and your upcoming events this month.

TaLana Hughes: Thank you.

Domonique Davis: Diving right into our questions, just want you to tell us about your experience guiding, your daughter and other people who are transitioning to colleges and universities with preparing to handle their care. And what are some of the common questions and concerns that folks may have?

TaLana Hughes: So, there's a lot. I think it really starts with preparing during the high school years or even way beyond college comes into the purview or the conversation. It's really in high school and making sure that you have a 504 plan or even sometimes if needed, an IEP. Those things offer accommodations for individuals with Sickle Cell Disease, and it's not necessarily

anything that has to do with their inability to learn or anything of that nature. But it really is to level the playing field and the opportunities for the individuals with sickle cell disease. So then, when planning to go to college some of those accommodations are kind of already set up or you're kind of used to the things that your child or young adult needs to be able to be set up for success in a school setting or even for college. And then, I would say, the first thing to do is definitely reach out to the Office of Disability on college campuses because that is then what looks like the place similar to high school where you would get accommodations set up.

Domonique Davis: What's one piece of advice, or more, I'm sure you have a lot with your background of helping your own child navigate this, what advice do you give a family or caregiver preparing their child for college transition?

TaLana Hughes: So, we are literally in that process and have been in that process, I would say the past two or three years now. Tiana's now in her sophomore year of college, but would've been in her junior year, but had to take a medical leave of absence. And I think just having real conversations. Of course, we all have expectations when going to college, but then having to deal with a chronic condition on top of just wanting to fulfill all and check off all the other boxes of expectations of wanting to go to college and be done in four years. I think the conversation that I have a lot with my daughter is that there is no certain timeframe to complete. You know, just pretty much have a plan in place, and that goes forward. Whatever major you think you want to have when you start out, which may not stay the same each year, you know, you may end somewhere else. Just really living in the moment and taking the experiences of taking different classes and trying to find your passion. But in addition to that, making sure that you stay heavily connected with the Office of Disability, and then individually with each of your professors because it's different from professor to professor. One approach may not be the same for each, and it's almost like starting over again each semester and kind of re-explaining those needs that you have or accommodations. If you need more time to get to class. If you know you need more testing time or if accommodations are more specific around you getting hospitalized while in college and missing classes. What will it look like if I fall behind and I need to make up? Just really seeing the room for flexibility.

The importance is just that communication. That has kind of helped my daughter to be most successful because she continues to communicate with her professors, communicate with the Office of Disability, the advisors that are there, really tapping into all the resources that are available, whether it's during an emergent time or being prepared for when that emergent time arises. Because the whole idea is that I can't be there. Yeah, she's not that far away at college. So, location definitely is important. She's not that far, but far enough to be independent. I mean, they still want to have their independence. Just really being comfortable advocating for themselves, in the absence of me or us as parents.

Because things will have to get accomplished and take place without our ability to always be there. So just kind of preparing them as best as possible to be an advocate for themselves.

Domonique Davis: That's so important. And it's a transitional time in general. So, to doubly be loaded with having to now manage your own care a bit more, I can imagine that it's an ongoing process, it's a lot.

TaLana Hughes: The best thing to do is just stay open-minded. It's stressful. Tiana is one of three kids, so I did have an older daughter that had the ability to kind of just get out there and figure things out for themselves. I still get phone calls from Tiana, like, "Hey, I'm having some pain. What do you think I should do?" And it's like, "Start your pain management regimen. Still, try to go to class if you feel up to it." No stress on top of your figuring out what works best for them, as they're the individual that's at school and that may not necessarily always agree or align with what I want or what I would do.

Domonique Davis: I appreciate you joining, thank you for the wonderful work that you all are doing.