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Services for Young Adults with Chronic Pediatric Onset Conditions, A Problem Nationwide

Comprehensive services for children with special health care needs has been a priority nationwide and has prevented morbidity and mortality for this special needs population. As this population is aging, similar comprehensive services in the adult setting are lacking. This problem has been recognized nationally and is addressed in 2010 Express. Implementation of the *State Genetics Plan* will facilitate attainment of adult medical homes for young adults with special health care needs.

The Smith sisters were both diagnosed as having sickle cell disease (SCD) as infants. Until 2 1/2 years ago they received their medical care through the Comprehensive Sickle Cell Program at Children's Hospital in Oklahoma City. Now that they are both over 21 years of age they are no longer eligible to receive full services at the Children's Hospital. The Sickle Cell Program staff continued to see them in clinic for a while. However, patients over 21 years of age cannot be seen in a pediatric emergency room. This is a significant problem for patients with SCD since they face unpredictable emergency situations because of the nature of their disease. Unfortunately there is no specific program for adults with sickle cell disease in Oklahoma. With help from the Pediatric Sickle Cell Program staff, Kayla and Dewayna found a physician willing to take them on as patients. Two years later they were asked to discuss their experience.

Dewayna's Story: The medical staff in the adult clinic seemed to think more about business and seemed less compassionate. They did not seem to know much about how to treat sickle cell and did not want to hear about what has worked for me in the past. I was fussed at by the medical staff when I showed emotions about hurting. Several times I was told that I could go somewhere else if I didn't like the way I was being treated. I felt stuck and had to put up with the way they treated me because it is hard to find doctors who want to treat people with sickle cell disease. When I contacted the doctor's office after hours for what I had been taught was an emergency, I was just told to call back the next day. Another time I went to the hospital ER when I had fever. The pediatric staff had told me that fever over 101^0 F is an emergency for a patient with sickle cell disease and that I MUST come in for a blood culture and a dose of antibiotics through an IV. But I was not given antibiotics and when I asked about getting a culture I was told that I did not need one since my doctor had ordered one a few days before. I tried to show the doctor the letter about fever from the pediatric doctor but he didn't want to see it! I was sent home with Lortabs and ibuprofen for pain even though I was not hurting. I ran a fever the next day too. I didn't go to the hospital because they didn't do anything for me the other night. I just stayed home and hoped that I would not get really sick.

Kayla's Story: They make me feel like it's my fault because I am sick. I can't show any emotions when I am hurting because they will get mad at me. Sometimes they take me into another room when they are doing certain procedures so I won't upset the other patients. They don't like to be told what to do or what works best for me. I have been on a chronic transfusion program since I was 14 because my pain was so bad that I was hardly ever able to go to school. I know that too much iron in my body can be dangerous and that I have to have regular tests to check it. I asked for a liver biopsy to check my iron because my ferritin level was going up. They just brushed me off. I also asked about getting some preventive services such as eye exams and a heart ultrasound but all they said was "we don't do that."

Mother's Story: I am concerned that one of my babies is going to die. Those people don't know how to treat people with sickle cell disease and they get mad when the girls or I tell them about what works for them. The fact that I am a nurse does not help although you would expect that it would. At times I feel desperate. I wish so much that there was a special program for adults with sickle cell disease to advocate for my family and people like us.