Interview with SCD stakeholder

Larry is a 51 year old male living with SCD. He was forced to retire early after suffering his second stroke. He does not have children and he was not diagnosed via newborn screening. When he was a child, growing up in a rural area, his mother would have to drive an hour to take him to a specialist. Both of his brothers passed away from complications of SCD. As a representative for a sickle cell disease association that provides education and limited direct financial support, he works with a wide variety of families and individuals affected by SCD. Based on these relationships he has observed the following:

Every case is very individual, but a lot of families often don't know where to go to seek testing and treatment. Primary care providers don't know where to send patients and don't know who they can go see.

Experience of one grandmother: granddaughter was born to a single mother who took her child to the local children's hospital. Testing confirmed what was found on the NBS – SCD – but was unable to definitively determine the genotype without testing both the mother and the father. Father was unwilling to cooperate and get tested. It wasn't until two years later that they were able to determine the type of SCD and effectively treat the child.

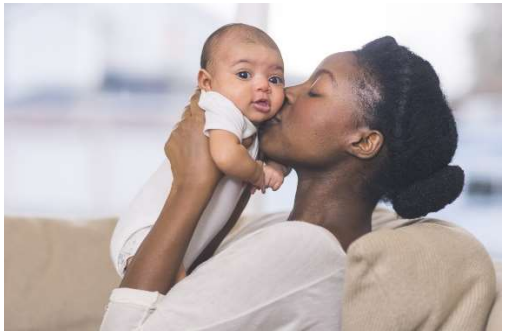
Many parents have very limited knowledge about the disease, and there's a lack of education given to parents when they get a new diagnosis or screening results. They don't understand what the disease means for their child.

Because of this, it's hard for parents to wrap their head around the idea of doing testing and treatment when their child isn't showing symptoms – isn't sick and crying. They don't believe the child has the condition. This also combines with a long history of distrust with the health care system. Hard to get them to schedule because of this.

Cultural beliefs also keep families from getting testing or treatment or support – believe SC is a curse. Can't talk about it in the family and affects family dynamics. One family would lose royal benefits if their family in Africa learned that their child has SCD. There's a fear of even getting support and going to support groups because of pictures getting on Facebook and making their way back to family.

Yes, lack of insurance coverage and out of pocket costs are also barriers. Even when families qualify for Medicaid, but previously had no reason to be on it, because they don't get sick. So, all of a sudden, they need it but aren't on it.

But health care coverage isn't the only barrier to care: location and availability of providers is a barrier too. Growing up in a rural area, Larry and his mom had to drive over an hour for him to see a specialist. This is a huge burden for families that don't have paid sick leave, plus the cost of gas, or possibly not even having a highway worthy vehicle.



Marcy (Age 23) & Leyla (Age 2)

Occupation: Walmart Assistant Store Manager

Education: High school diploma

Marital Status: Not married

Insurance Status: Employer Provided Ins.

Living situation: Lives with mom

Location: Sabetha, KS (~100 mi. NW of Kansas City, KS; population 2,519)

Her Story:

At the time Leyla was born, she and Marcy were uninsured. Marcy was working two part time jobs. For cultural and religious reasons, Leyla's biological father is not involved in their lives. About a week after Leyla was born, Marcy received a letter stating that her daughter's newborn screening was abnormal for a hemoglobin disorder. She didn't know what the newborn screening was and didn't know what a hemoglobin disorder was. As a new mom who was having to prepare to go back to work soon, and because Leyla appeared happy and healthy, Marcy didn't worry about the letter and forgot about it.

A few weeks later, she got a voicemail from the hospital where Leyla was born. The nurse stated that they were trying to reach her to find out who Leyla's pediatrician was so they could forward an abnormal newborn screening report. By the time she got home from work and had Leyla in bed, she had forgotten about it again. When the nurse called during her lunch break the next day, she answered the phone. The nurse said that Leyla was sick and needed to be seen by a pediatrician right away for more tests. The nurse didn't give Marcy much information about Sickle Cell Disease and Leyla still appeared happy and healthy. So, given Marcy's unpleasant experience with the hospital nurses during Leyla's birth, Marcy was skeptical and guarded during the call. she was unsure about the information she was given and didn't think her daughter really needed to be seen by a doctor, or that she needed tests that she couldn't afford anyway. Additionally, she wasn't sure that she or Leyla would qualify for Medicaid because of living with and receiving support from her mom.

When Leyla was about 5 months old, one of the day care employees noted that Leyla had been sleeping more and seemed fussier when she was awake. Then, when Leyla was 6 months old, the day care called her saying that Leyla seemed like she might be sick - that she hadn't stopped crying all morning and that her toes looked swollen. They asked her to pick Leyla up and suggested they take her to the doctor. Leyla continue to cry or be fussy or sleepy the next day, and Marcy noted that her toes and fingers were still swollen. Worried, Marcy took her to urgent care. The doctor there said that nothing appeared to be wrong, and that Leyla's fingers and toes might be swollen because of how much she had been crying.

When Leyla was 7 months old, Marcy became a full-time Walmart employee and signed up for health insurance. When she took Leyla to the doctor for her 6-month checkup and vaccinations (which the day care had been reminding her to do), the doctor asked if she knew about Leyla's newborn screening results. The doctor explained that Leyla's illness at 6 months old was likely related, and that more testing needed to be done to determine if Leyla had Sickle Cell Disease or not.

Initial testing confirmed the screening results, and they made an appointment to see the specialist in Kansas City. Because of the long drive both directions and Marcy had to request a whole day of leave from work to go. The specialist said that both Marcy and Leyla's father would need to be tested so that they could determine Leyla's genotype. Unfortunately, despite Marcy's and her mom's multiple requests since then, Leyla's father has been unwilling to cooperate and get tested. As a result, Leyla's treatment options are limited, and she's been sick more often as she's gotten older.

Marcy (23 years) Persona

Fears:

- Marcy worries that her employer will fire her because of too many time-off requests from her daughter being sick and for Leyla's doctor appointments.
- She worries that they'll miss follow up appointments with the specialist because of the time and cost to drive all the way to Kansas City, and because their car is older and is often broken down.
- Marcy is concerned that Leyla's father will never agree to get tested and that Leyla will be sick more often because of limited treatment options.

Hopes:

- Marcy hopes that Leyla's current treatment plan will keep her healthy enough to enjoy her childhood and do well when she goes to school.
- She wants to continue earning promotions at work so she can move closer to Kansas City to be closer to the specialist.
- She hopes that since Leyla's been sick more often, that her father will agree to get tested.
- Marcy hopes that one day more treatment options are available, and that Leyla is a candidate for stem cell transplant or gene therapy.

Marcy (23 years) Empathy Map

I don't feel comfortable at the local clinic

The system isn't made so I can be successful

I want to be self-sufficient

"I can't treat your daughter unless her father gets tested too."

I'm smart but I feel like people don't see that

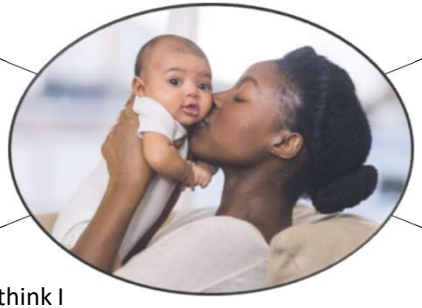
I wish I had more support

"Crying a lot can make your baby's fingers and toes swell up."

Thinking/Feeling

"You're up for termination if you earn 5 points for calling out sick, even it's because your daughter is sick."

Hearing



Seeing

"In my culture, Sickle cell is a curse. So, I can't be involved."

"I didn't think I was eligible for Medicaid."

Saying/Doing

"I had too much to worry about and was too tired as a new, working mom to remember the letter I got"

"I didn't understand what SCD meant for my daughter"

"I had no reason to believe the nurse. I don't trust them, and my daughter wasn't sick."

Unsure who to trust

Anxious

Inadequate

Guilty

Angry

Determined

Skeptical

Other mothers at day care who's children appear healthy and who appear prosperous

Hopeful

Coworkers who don't take as much sick leave

Healthcare providers that don't look like her & don't understand her situation

A single healthcare system in Sabetha with limited providers

Driving 1.5 hours each direction for specialist appointments

Taking extra shifts to cover out of pocket medical costs

Missing appointments because of car problems

Living with mom to save money

Frustrations:

- There aren't a lot of options for specialists
- No one talked about Medicaid eligibility
- Limited treatment options
- Limited testing options
- Not enough work flexibility
- Urgent care doctor gave incorrect information
- Nurse gave little information

Desires:

- Keep Leyla healthy for school and play
- Increase earning potential
- Decrease travel time and missed appointments
- Stem cell transplant or gene therapy