



Utah health status update

Key findings

- People who have sickle cell disease (SCD) tend to have a poorer quality of life and reduced life expectancy (estimated average is 54 years) compared to people without SCD (77.5 years).
- The DHHS Office of Health Equity conducted interviews with healthcare providers and people who have SCD in Utah to come up with recommendations to improve SCD treatment.
- People who have SCD in Utah experience many challenges when they access healthcare, including finding knowledgeable providers, maintaining insurance coverage, being heard and treated with respect, and receiving necessary resources and support.

Sickle cell disease in Utah: recommendations based on patient experiences

Sickle cell disease (SCD) is a group of inherited red blood cell disorders caused by a genetic mutation which results in sickle-shaped cells that reduce oxygen-carrying capacity.¹ Pain is the most common complication of SCD and often sends patients to the emergency room.² Patients with SCD require specialized and well-coordinated medical care.³ Individuals with SCD tend to have a poorer quality of life and don't live as long (estimated average is 54 years) compared to individuals without SCD (77.5 years).^{1,3} In compliance with H.B. 487 Sickle Cell Disease (2023 General Session), the Department of Health and Human Services (DHHS) Division of Population Health produced a legislative report; the Office of Health Equity (OHE) was assigned to the qualitative component of the report. OHE conducted interviews with healthcare providers, SCD patients, and caregivers to incorporate their experiences and challenges into recommendations to improve the surveillance, screening, diagnosis, and treatment of SCD among people living in Utah.

Between March and May 2024, OHE interviewed 17 people with SCD (or caregivers of those with SCD), ranging in ages from 12 to 67 years old. A majority of patients identified as Black/African American or

The following are a list of the recommendations to improve treatment for people with SCD in Utah. To read the full details, visit [this report](#):

1. Develop a sickle cell disease registry or surveillance system in Utah.
2. Improve standards of care and access to health insurance.
3. Increase SCD education and training for providers.
4. Provide patient resources and support.
5. Increase SCD awareness.
6. Create a time-limited SCD task force.





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of African descent, with others identifying as Hispanic/Latino, White, and Middle Eastern/North African. OHE interviewed 4 healthcare providers—3 hematologists/oncologists with specialized SCD training and 1 social worker with extensive experience with patients with SCD and other blood-related genetic conditions. Interview questions focused on overall experiences living with SCD in Utah, challenges to accessing care, quality of care received in Utah, and recommendations to improve both the healthcare and quality of life for people with SCD in Utah. A summary of challenges identified in the interviews are outlined below.

Standard of care and access to health insurance

Utah lacks a dedicated SCD treatment center which leads to an inconsistent standard of care depending on where patients receive treatment and the knowledge and experience of the healthcare team. All providers noted that fragmented care between inpatient, outpatient, and health systems severely impacts treatment. Both patients and providers identified insurance coverage as a major barrier—patients often cannot access hematologists who specialize in SCD if they are outside their insurance network, especially during hospitalizations. Many patients also reported they lost coverage or had insufficient insurance to manage high medical costs. These challenges peak when patients transition from pediatric to adult care, a period with a sharp increase in mortality.⁴ Additionally, Utah lacks a surveillance system to track SCD prevalence and cost burden.

Education and training for providers

Every healthcare provider, patient, and caregiver cited the lack of SCD training among Utah healthcare providers as a significant challenge. A majority of patients shared that providers often do not know how to treat SCD which leads to complications and puts lives at risk. Providers noted that many hematologists are focused on oncology, not classical hematology which limits their expertise in SCD. Additionally, primary care, emergency, and pain management providers have limited experience treating SCD. One patient explained, “I feel like every time . . . I’m their very first patient with SCD, and as a doctor they probably heard about SCD but they never had a patient and [it’s their] first time giving care [to an SCD patient].”

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Dismissal and unfair treatment

Many patients and caregivers reported feeling dismissed or not heard or believed when they discuss their pain with healthcare providers. The lack of awareness about SCD’s severity makes it difficult for patients to communicate their needs. They must advocate for themselves, and often face stigma and are accused of drug-seeking behavior. One patient shared, “I wish people took me more seriously and I wish people viewed me a little more human.” Patients also shared experiences of unfair treatment due to their race. The challenges of managing multiple health conditions further complicates their experiences in seeking appropriate treatment and being heard by their care teams.

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Patient resources and support

All patients and caregivers who were interviewed reported a lack of resources and information for people with SCD in Utah. Many felt uninformed about their condition and did not know where to find helpful information. Both patients and caregivers emphasized the toll SCD takes on patients' and family members' mental health, with many describing the condition as isolating which can often leave patients feeling alone and frustrated. One patient said, "It's a very isolating disease. It's very sad," with another sharing, "People feel discouraged when they can't do anything, so that leads to feeling lonely." Caregivers also expressed feelings of worry and exhaustion, constantly anticipating the next sickle cell crisis.

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SCD awareness

Lack of public awareness about the severity of SCD was a common challenge. Patients and caregivers reported difficulties in schools and workplaces due to limited understanding and accommodations for SCD. Many students with SCD, from elementary school to college, do not receive necessary support, and employers often fail to accommodate their needs. Because of this, many people with SCD expressed frustrations with having to drop out of school or quit their jobs. The lack of accommodations to pursue higher education and a career puts these patients further behind socioeconomically and can often leave them feeling hopeless and isolated.

1. Centers for Disease Control and Prevention. (2024, May 15). *Sickle Cell Disease (SCD) | Sickle Cell Disease (SCD)*. CDC. Retrieved May 21, 2024, from <https://www.cdc.gov/sickle-cell/index.html>.

2. Centers for Disease Control and Prevention. (2024, May 15). *Complications of SCD: Pain*. CDC. Retrieved October 17, 2024, from <https://www.cdc.gov/sickle-cell/complications/pain.html#:~:text=Pain%20is%20the%20most%20common,throughout%20the%20body%2C%20causing%20pain>.

3. Luloh, M., Heath, L., Gonzales, V., Knippenberg, K., & LaFleur, J. (2023, October). *Utah Medicaid DUR Report October 2023: Sickle Cell Disease in Utah* [Report]. University of Utah College of Pharmacy: Drug Regimen Review Center. https://drive.google.com/drive/u/0/folders/1jBalgm9Eu6mKEO2z_4iDyt8yGXs8hb-Z.

4. Fasipe T, Dongarwar D, Lopez E, et al. Hospital use and mortality in transition-aged patients with sickle cell disease. *Hosp Pediatr*. 2021;11(12):1303-1310. doi:10.1542/hpeds.2021-005806.

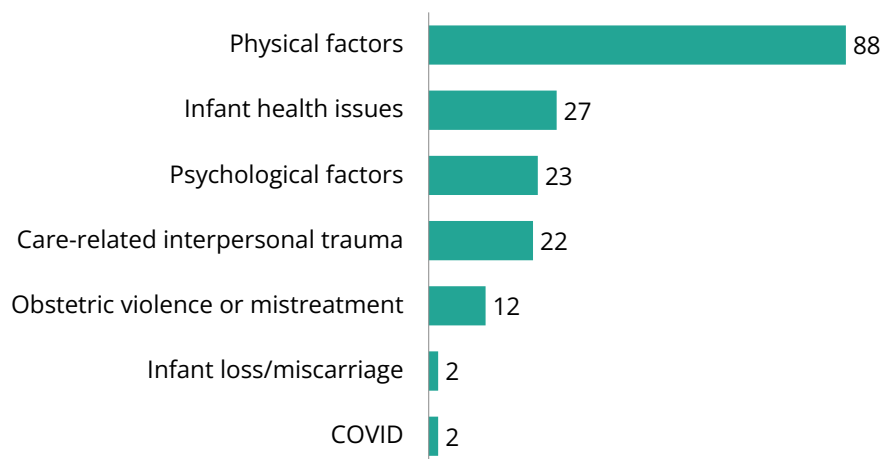
Birth and postpartum trauma

Birth and postpartum trauma is when a woman has a bad experience during or after birth that can cause lasting problems and even when the baby is born healthy Birth trauma is determined by the individual.¹ Estimated rates of birth and postpartum trauma vary from 33–45%.^{2,3} An estimated 3–5% of women experience post-traumatic stress disorder (PTSD) related to a birth or an after birth experience.⁴ In high-risk groups, such as women who have depression and infant complications, PTSD is even more common, up to 15.7%.⁵ There are many contributing factors in collecting and reporting birth and postpartum trauma data.

The Utah Women and Newborns Quality Collaborative (UWNQC) is a group of maternal and child health professionals who work together to improve maternal health among women in Utah. One of these projects focuses on bridging the gap between what happens when birth and after birth trauma occurs and connecting the affected women through education, validation of their experience, and connection.

Education efforts to increase awareness about birth and after birth trauma included the launch of a new webpage which offers birth trauma resources (<https://mihp.utah.gov/birth-trauma>) and educational sessions for health care providers. A UWNQC staff member who experienced a traumatic birth event has also interviewed 38 women who say they had a traumatic birth or after birth experience. These interviews give validation to the participants and contribute to gathering some of the causes of birth and after birth trauma. Early data from these interviews can be seen in Figure 1, which lists the causes of birth trauma by category. The categories used were based on the ones used by the [Maternal Mental Health Leadership Alliance](#).³ Most of the women who were interviewed reported there were a number of causes for their traumatic birth experiences. More than 60% reported at least 5 causes of birth trauma. The data collected from these interviews shows that most women report multiple causes of trauma, with the primary contributor being physical factors. A summary report is planned for release in 2025.

Figure 1. Birth and postpartum trauma by category (n=38)



Source: Utah Women and Newborns Quality Collaborative traumatic birth interviews

1. Greenfield, M., Jomeen, J., & Glover, L. (2016). What is traumatic birth? A concept analysis and literature review. *British Journal of Midwifery*, 24(4), 254–267. <https://doi.org/10.12968/bjom.2016.24.4.254>.

2. March of Dimes (2023). The toll of birth trauma on your health. <https://www.marchofdimes.org/find-support/topics/postpartum/toll-birth-trauma-your-health>.

3. Maternal Mental Health Leadership Alliance (2023). Birth Trauma and Maternal Mental Health Fact Sheet. <https://www.mmhla.org/articles/birth-trauma-and-maternal-mental-health-fact-sheet>.

4. Kranenburg, L., Lambregtse-van den Berg, M., & Stramrood, C. (2023). Traumatic Childbirth Experience and Childbirth-Related Post-Traumatic Stress Disorder (PTSD): A Contemporary Overview. *International journal of environmental research and public health*, 20(4), 2775. <https://doi.org/10.3390/ijerph20042775>.

5. Grekin, R., & O'Hara, M. W. (2014). Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis. *Clinical psychology review*, 34(5), 389–401. <https://doi.org/10.1016/j.cpr.2014.05.003>.

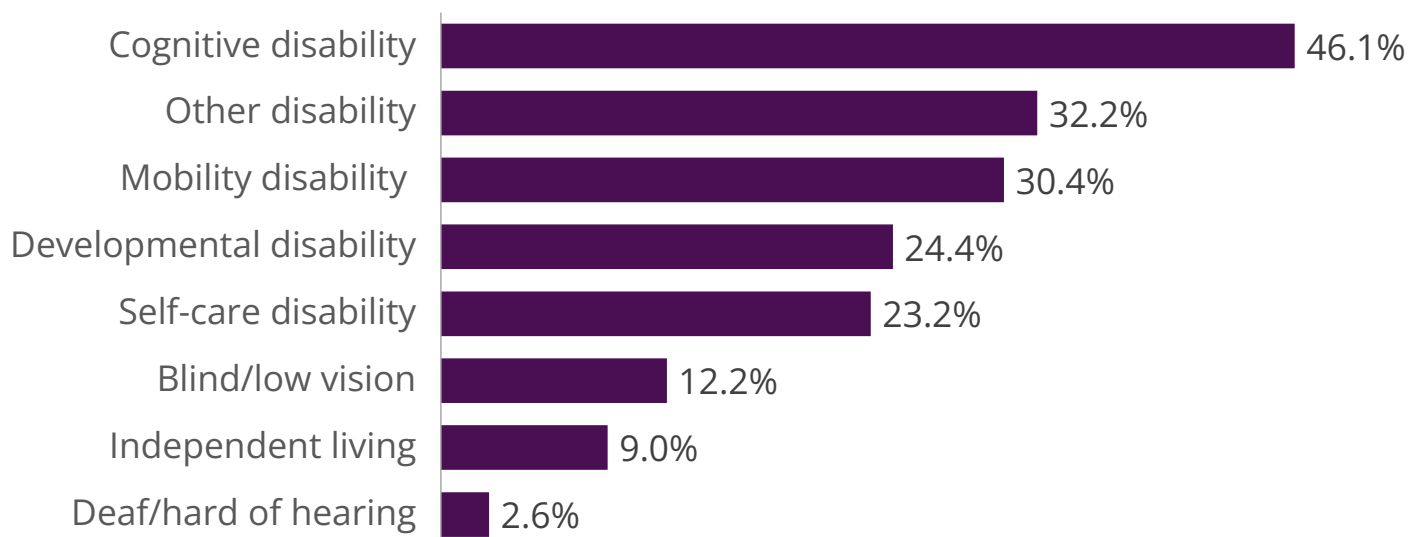
How disability and LGBTQ+ identity intersect: findings from the Utah LGBTQIA+ Health Needs Assessment

Having 1 or more disabilities affects not only health status and health outcomes,¹ but it also affects experiences accessing and using various healthcare services and health programs.² Because people who have disabilities represent diverse people with many different identities, it is important to understand how these identities intersect with how health is affected. The Utah LGBTQIA+ Health Needs Assessment was a statewide survey used to gather information on the health status and health experiences of people who identify as LGBTQIA+.

Results

The results represent only survey respondents who selected they had at least 1 disability (n=347). Cognitive and other disabilities were the most common disability types reported (Figure 1). Among other disabilities, the most common included mental health conditions, chronic illnesses, and various intellectual and developmental disabilities such as autism and attention-deficit/hyperactivity disorder (ADHD).

Figure 1. Percentage of self-reported disability types among LGBTQIA+ adults in Utah (n=347)



Source: Utah LGBTQIA+ Health Needs Assessment survey

Note: Multiple selections were allowed so percentages will not add to 100%.

Experiences receiving healthcare

More than half (53.9%) of respondents reported they felt stigmatized or discriminated against when they looked for healthcare. When they receive care, 77.9% of respondents reported they experienced discrimination based on their LGBTQIA+ status while 36.2% felt they were treated with less respect because of their disability status. Negative experiences with healthcare providers can create barriers to receiving needed care.³

Barriers to receiving healthcare

Among those who responded, 88.2% reported they experienced barriers when they tried to access healthcare. Although 42.4% reported they had a routine checkup within the last 12 months, 21.7% did not have a personal doctor or healthcare provider. Additionally, 34.1% often or always worry when they need healthcare because of past or possible negative reactions from healthcare

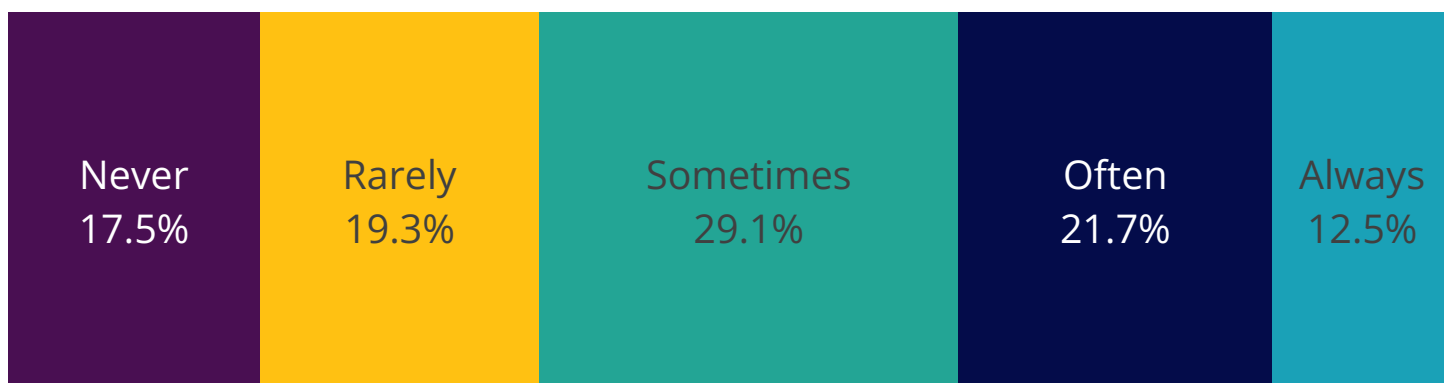
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providers (Figure 2). Respondents also do not feel their healthcare providers have the right expertise to treat their health needs as an LGBTQIA+ person, with only 18.8% of respondents who feel extremely or very confident in their healthcare providers. These and other barriers may limit the access and use of healthcare services among people who identify as both LGBTQIA+ and having a disability.

Figure 2. Frequency of respondents who feel worry when they need healthcare because of past or possible negative reactions from healthcare providers



Source: Utah LGBTQIA+ Health Needs Assessment survey

Resources to address barriers

The Disability and Health Program provides resources to individuals and healthcare providers to promote the health and well-being of people with disabilities. These resources are available to people with disabilities, including individuals who identify as LGBTQIA+. The Linkage Project was launched to connect people with disabilities to resources to address unmet healthcare needs. Visit the [Linkage Project](#) to enroll or refer someone to participate. Trainings are also available to healthcare providers to increase competency to treat and communicate with people with disabilities.

1. Utah Department of Health and Human Services. Health disparities among Utah adults with disabilities. <https://healthyaging.utah.gov/wp-content/uploads/Disability-and-Health-Needs-Assessment-Report.pdf>.

2. Utah Department of Health and Human Services. Utah health status update. December 2023. https://ibis.utah.gov/ibisph-view/pdf/opha/publication/hsu/2023/2312_Disability-RaceEth.pdf.

3. Utah Department of Health and Human Services. Utah health status update. September 2024. https://ibis.utah.gov/ibisph-view/pdf/opha/publication/hsu/2024/2409_VetSuicide.pdf.