IHPI BRIEF

State-University Partnership to Enhance Outreach to Adults Living with Sickle Cell Disease in Michigan

INSTITUTE FOR HEALTHCARE POLICY & INNOVATION
UNIVERSITY OF MICHIGAN

Sickle cell disease is the most common inherited blood disorder in the U.S.

Sickle cell disease is associated with significant health complications across the life span, such as pain, stroke, and infection, as well as reduced average life expectancy of 45 years.[1–2] Access to consistent high-quality healthcare improves health outcomes among this population.[2] However, the risk for adverse outcomes is further heightened as over 90% of people with sickle cell disease in the U.S. are Black or Hispanic — racial and ethnic groups that have historically been economically and socially marginalized and often underserved in healthcare.[3]

There are over 4,000 individuals living with sickle cell disease in Michigan, the majority enrolled in Medicaid.[4] Historically, Michigan residents up to 21 years of age living with sickle cell disease were eligible to receive health coverage through Children's Special Health Care Services (CSHCS), a program within the Michigan Department of Health and Human Services (MDHHS) that serves children and some adults with special health care needs regardless of eligibility for other insurance coverage. The program is part of the federal Title V Maternal and Child Health Services Block Grant. CSHCS assists with reimbursement for medical care and treatment, including co-pays, deductibles, and transportation, and provides care coordination, case management, and other support services.

In October 2021, Michigan expanded CSHCS coverage to include people living with sickle cell disease over 21 years of age with the goal of improving health outcomes and reducing health disparities for this vulnerable population.[5]

In order to successfully implement this new expansion, the first step was to identify as many eligible people as possible. **MDHHS partnered with the Michigan Sickle Cell Data Collection (MiSCDC) program at the University of Michigan to identify adults with sickle cell disease who are newly eligible for CSHCS coverage.** The MiSCDC program uses multiple population-level data sources to identify people with sickle cell disease in Michigan (see page 2 for further details).[6]

Key outcomes of the state-university partnership

The collaboration between MDHHS and the MiSCDC program at the University of Michigan substantially increased identification of adults eligible to enroll in the CSHCS program expansion.

The partnership identified 2,569 adults living with sickle cell disease in Michigan who are eligible to enroll in the new CSHCS expansion.

- Initially, 400 eligible people were identified using CSHCS enrollment data.*
- An additional 2,169 eligible people were identified by leveraging the multi-source MiSCDC database.
- Of the additional people identified, 24% were adults who had been enrolled in CSHCS prior to 2015 and 76% were adults who had never been previously enrolled in CSHCS.

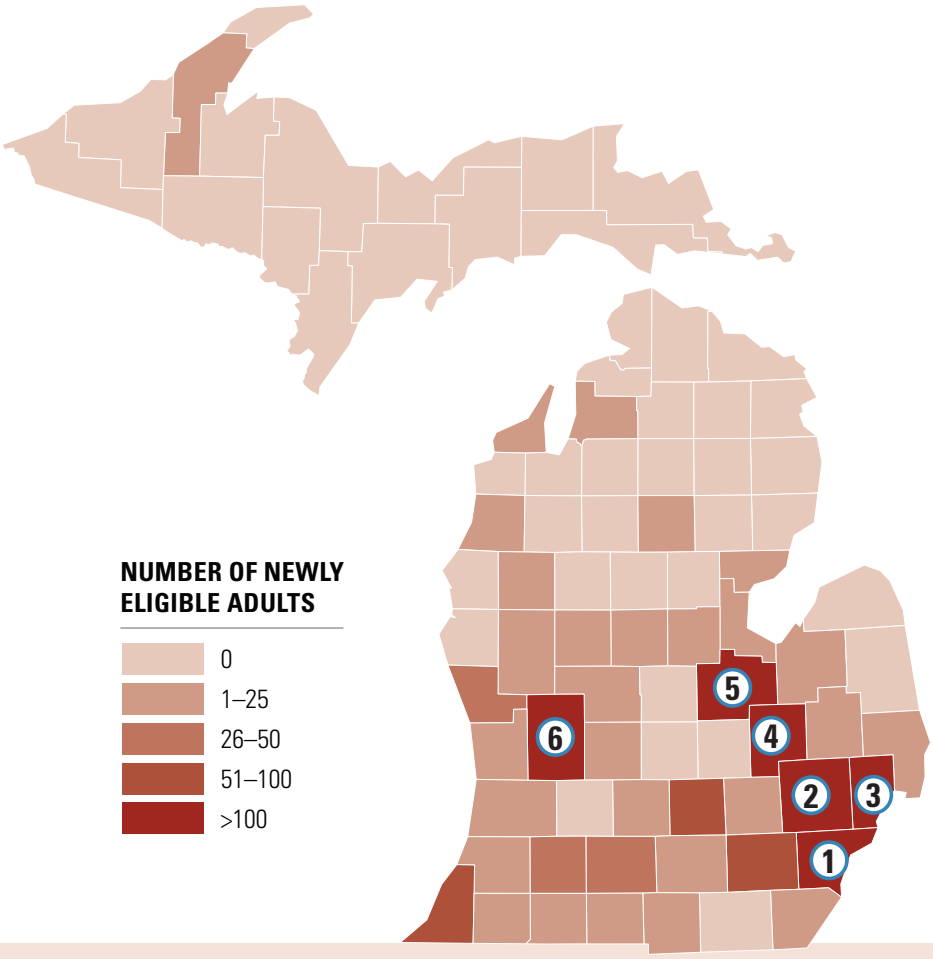
2,569 total adults identified

2,169 additional adults identified using the MiSCDC database

400 adults identified using recent CSHCS enrollment*

**CSHCS program enrollment data from 2015-2022 was used to identify people who had been unenrolled due to reaching the prior age cap of 21.*

Half of all Michigan counties are home to adults with sickle cell disease who are newly eligible to enroll in the CSHCS expansion, with the majority living in southeast Michigan.



Counties in Michigan with >100 newly eligible adults living with sickle cell disease

1. **1,117** Wayne
2. **256** Oakland
3. **213** Macomb
4. **180** Genesee
5. **117** Saginaw
6. **109** Kent

MICHIGAN SICKLE CELL DATA COLLECTION

What is the Michigan Sickle Cell Data Collection (MiSCDC) program?

MiSCDC merges numerous sources to gather population-level data to identify people living with sickle cell disease in Michigan and understand their health and healthcare over time.[6] The data is used to assess gaps in programs and policies related to sickle cell disease. Acquisition and analyses of data to conduct surveillance are made possible through a grant of public health authority authorized by MDHHS.

MiSCDC data sources include: Sickle cell disease clinics in Michigan and state-maintained data such as newborn screening, Michigan Medicaid, Children's Special Health Care Services, immunization registry, vital records, and comprehensive all-payer databases.

MiSCDC is a collaboration led by the Susan B. Meister Child Health Evaluation and Research Center at the University of Michigan and MDHHS and is funded by the Centers for Disease Control and Prevention (CDC). There are 10 other states with CDC-funded sickle cell data collection programs like MiSCDC.[7]

What does this mean for health policy discussions?

To successfully implement Michigan's new policy to extend CSHCS benefits to adults with sickle cell disease, a key step is to identify eligible participants.

The partnership between MDHHS and the University of Michigan allowed the MiSCDC team to leverage a multi-source dataset to identify five times as many eligible people for the program expansion compared to relying on prior CSHCS enrollment data alone. This demonstrates the usefulness of state-university collaborations and creative strategies to improve the health and quality of life for populations that may be hard to reach.

Other states, particularly those who have Sickle Cell Data Collection (SCDC) programs, could consider using similar methodologies to identify individuals with sickle cell disease—or other rare diseases—who can be connected to resources and impacted by new policies and program expansions.

Going forward, the MiSCDC team plans to continue partnering with MDHHS to evaluate enrollment and health-related outcomes of the CSHCS program expansion as well as explore strategies to identify and enroll children that are currently eligible for CSHCS.

References

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