

ASSESSMENT REPORT:

2015-2018 Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan



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The **Assessment Report: 2015-2018 Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan** was written as a contributing report to the Michigan Department of Health and Human Services' (MDHHS) ongoing public health planning efforts to address sickle cell disease (SCD) in Michigan. The report serves as an environmental scan for Michigan's 2025 SCD strategic planning process, documenting the status of activities identified in the original strategic plan, as well as highlighting other accomplishments that have occurred to date since the release of the first strategic plan in 2015.

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COMMONLY USED ACRONYMS	
Acronym	Meaning
AAMC	American Association of Medical Colleges
AIM	Alliance for Immunization in Michigan
ASH	Association of Hematology
BRAIN	Better Radiology Access to Improve Neurological Outcomes
CBO	Community Based Organizations
CDC	Centers for Disease Control and Prevention
CEO	Chief Executive Officer
CGT	Cell and gene therapies
CHEAR	Susan B. Meister Child Health Evaluation and Research
CHAMPS	Community Health Automated Medicaid Claims Processing System
CHASS	Children's Healthcare Automated Support Services
CHM	Children's Hospital of Michigan
CMDS	Children's Multi-Disciplinary Specialty
CME	Continuing medical education
CMS	Centers of Medicare and Medicaid Services
CoE	Center of Excellence
CSHCS	Children's Special Health Care Services
CSN	Children with Special Needs Fund
CYSHCN	Children and youth with special health care needs
DMC	Detroit Medical Center
ECHO	Extension for Community Healthcare Outcomes
ED	Emergency department
EPHS	Essential Public Health Services
FAQs	Frequently asked questions

FQHC	Federally Qualified Health Center
FY	Fiscal Year
HemQIC	Hematology Quality Improvement Committee
HemQIP	Hematology Quality Improvement Program
HFH	Henry Ford Health
HRSA	Health Resources and Services Administration
HSA	Health Status Assessment
IEP	Individualized Education Program
IHP	Institute for Health Policy
LARA	Department of Licensing and Regulatory Affairs
LEGD	Lifecourse Epidemiology and Genomics Division
LHD	Local health department
MDE	Michigan Department of Education
MDHHS	Michigan Department of Health and Human Services
MGN	Midwest Genomics Network
MHP	Medicaid health plan
MiSCDC	Michigan Sickle Cell Data Collection Program
MITT	Michigan Interagency Transition Team
MMWR	Morbidity and Mortality Weekly Review
MPHA	Michigan Public Health Association
MPHI	Michigan Public Health Institute
MSU	Michigan State University
NBS	Newborn screening
NHLBI	National Heart, Lung, and Blood Institute
NICHQ	National Institute for Children's Health Quality
PCP	Primary care provider

PDSA	Plan, Do, Study, Act
PHG	Public Health Genomics
P-SCIP	Pediatric Sickle Cell Improvement Program
SCD	Sickle cell disease
SCDAA-MI	Sickle Cell Disease Association of America-Michigan Chapter
SCCEE	Sickle Cell Clinical Expansion and Enhancement
SCT	Sickle cell trait
STORM	Sickle Treatment and Outcomes Research in the Midwest
UM	University of Michigan
VFC	Vaccine for Children
WIC	Women, Infant, and Children's Supplemental Nutrition Program

INTRODUCTION

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States (U.S.) and is associated with early mortality and substantial morbidity. SCD is an autosomal recessive genetic disease. The majority of the ~100,000 individuals living with SCD in the U.S. are racial and ethnic minorities.¹ In Michigan, approximately 4,000 residents live with SCD² and approximately 140,000 people are sickle cell trait (SCT) carriers. According to the Michigan Sickle Cell Data Collection Program (MiSCDC), within the U.S., “individuals with SCD are at a high risk of early mortality for both men (42 years) and women (48 years), a reduction in average life expectancy of more than 20 years compared to those without SCD. SCD is associated with substantial morbidity, such as severe pain crises, acute chest syndrome, stroke, and infection, which leads to numerous health care encounters. The burden of SCD is substantial, in terms of financial implications and quality of life. It significantly affects those living with the disease, as well as families and the health care system.”³

As part of the state health department’s 2013 strategic planning process, a need to address SCD led to the development of ***Strategic Priority 2.4: Design a public health approach to SCD across the lifespan.*** A joint departmental effort, including the [Lifecourse Epidemiology and Genomics Division](#) (LEGD), the Family & Community Health Division, and [Children’s Special Health Care Services](#) (CSHCS), provided the staff needed to accomplish this strategic planning initiative. Beginning June 2014, the MDHHS SCD Strategy Team engaged in a mixture of planning activities in collaboration with the [Sickle Cell Disease Association of America - Michigan Chapter](#) (SCDAA-MI), the [Michigan Hematology Quality Improvement Program \(HemQIP\)](#), hematologists, nurses, and social workers, and individuals directly impacted by SCD. Michigan Department of Health and Human Services staff throughout the department, including those from the [Division of Immunization](#), [Michigan Medicaid](#), [Division of Maternal & Infant Health](#), the [Women, Infant, and Children’s Supplemental Nutrition Program](#) (WIC) and [state laboratory](#) programs, also participated in the planning process.

Strategic Planning Process

The planning process included the five steps described below and was designed to gather pertinent findings and experiences from research literature, community members, individuals with SCD, and health care providers.

Five Planning Process Steps Utilized:

1. Reviewed relevant literature and other state strategic plans.

2. Convened the newborn screening (NBS) HemQIC to gather input on important issues impacting this population, current and needed clinical medical management resources, underutilized opportunities to improve quality of life, critical public health focus areas, and health insurance opportunities to improve quality and access to health care resources.
3. Conducted five focus group meetings in Detroit, Saginaw, Lansing, Grand Rapids and Benton Harbor with individuals living with SCD and/or their caregivers. Recurring themes were extracted by the Strategy Team and reduced to seven focus areas: day treatment, transition, psychosocial/mental health, medication adherence, research, public education/awareness, and public/private insurance challenges.
4. Explored focus areas during discussions held at the strategic planning meeting held with community partners in October 2014.
5. Organized workgroups who identified critical issues, formulated strategies and tactics, and developed recommendations for each of the focus areas.

Seven key gaps were identified as public health priorities by planning participants. These included:

1. Need for education to emergency department (ED) physicians and ED guidelines to improve acute care for patients;
2. Lack of comprehensive transitional care programs;
3. Underutilization of community mental health and behavioral health services for psychosocial needs;
4. Lack of use and adherence to disease-modifying therapies such as hydroxyurea;
5. Need for better coordination of SCD research efforts;
6. More statewide-level education to increase awareness of SCD, SCT, and medical therapies; and,
7. Lack of providers who treat all aspects of SCD, with an emphasis on increasing providers for adults.

Recurring themes were extracted from the key gaps and reduced to seven goals, eight strategies, and detailed tactics specific for each goal. The goals promoted integration and expansion of SCD services and resources within existing public health programs and emphasized the need to enhance patients' clinical experience. The goals included in the state's 2015-2018 SCD Strategic Plan, are summarized below:

Education & Awareness: Develop a statewide multi-level messaging and communication strategy to increase awareness of SCD, disease-modifying medical therapies, and SCT.

Transition: Develop and implement strategies for improving the transition from pediatric to adult care.

Provider Shortage: Increase availability of primary and specialty care providers who treat all aspects of SCD, with an emphasis on increasing providers for adults.

Psychosocial/Mental Health Support: Increase recognition of the need to address psychological issues and provide mental health support.

Medication Adherence: Develop protocols for improving medication adherence in accordance with the National Heart, Lung, and Blood Institute's (NHLBI) Evidence-Based Management of SCD Guidelines.

Day Treatment Clinics: Improve acute care in the emergency room or alternative settings.

Research: Establish a Michigan SCD Consortium to coordinate public health research efforts in Michigan.

RESULTS SUMMARY

Although the department's first-ever SCD strategic plan's original timeframe spanned across 2015-2018, the plan subsequently became a decade endeavor as activities were developed, implemented, and expanded over time. Additionally, there were infusions of federal grant funding, legislative allocations, and opportunities to match specific projects as appropriate, which allowed the evolution of multiple initiatives. The overall goal of the plan was to execute public health interventions to reduce the burden of SCD in Michigan through improved awareness, comprehensive transitional care programs, and increased use of community mental health and behavioral health services.

While the work captured in this report is substantial, it must be noted that it does not catalog all the accomplishments. Not all activities were fully documented, and the data collection efforts were not centralized. As a result, the actual number of accomplishments associated with the 2015 Strategic Plan may be underreported.

However, the information compiled in this assessment can serve as a basis for understanding the status of priorities that have been addressed and gaps that still exist in systems of care. It also provides a backdrop for scanning the environment in which new planning activities and future programming will occur. By applying the 10 Essential Public Health Services framework (see Conclusion Section), MDHHS demonstrates the comprehensiveness of the 2015 Strategic Plan and its subsequent actions that enable optimal health for people with SCD, while seeking to remove systemic and structural barriers that have resulted in health inequities. Furthermore, by incorporating this framework, MDHHS continues to strive to fulfill its

vision to “*deliver health and opportunity to all Michiganders, reducing intergenerational poverty and promoting health equity.*” In the following section, the assessment will explore each strategic planning goal in depth.

GOAL 1: EDUCATION AND AWARENESS

To develop statewide multi-level messaging and communication strategies to increase awareness of SCD, disease modifying medical therapies, and SCT.



A major theme throughout the strategic planning process was the importance of increasing SCD and SCT awareness using a multi-tiered approach that maximizes patient, family, provider, and community knowledge to improve health and quality of life. Although SCD was first recognized over 100 years ago, there is still a lack of general knowledge about the condition. Therefore, a major focus of the strategic plan was to educate the public, consumers, and health and human service professionals about the SCD and SCT conditions and their impacts. This goal encompassed two main strategies:

Strategy 1: Increase activities with public and private organizations to raise awareness among targeted segments of the general and patient population about SCD/SCT and its implications.

Strategy 2: Increase capacity within MDHHS programs to incorporate SCD into public health programming.

More than 60 activities were completed within the education and awareness domain. Six activities involved developing or updating websites, applications, and listservs. Both MDHHS and SCDA-MI completed iterative updates to their websites, making them more user-friendly. The Midwest Genetics Network, along with McLaren Health Plan, offered new websites that contain sickle cell information specific to their unique programming. Additionally, the MDHHS Public Health Genomics Section (PHG) implemented a listserv, with a distribution list that has grown to over 150 professionals. Through this listserv, recipients receive quarterly updates that contain links to best practices and evidence-based/informed tools and resources.

Nine new, Michigan-specific resources were developed to ensure that patients, families, and health care providers are more knowledgeable about the disease and its treatments, as well as the standards of care and clinical guidelines associated with those treatments. These resources are easily accessible, printable, and available on public facing websites.

The SCDA-MI and MDHHS continue to partner to promote special events. Each year, the SCDA-MI sponsors events to remember World Sickle Cell Day on June 19 and Sickle Cell Awareness Month in September. The SCDA-MI organizes special events and t-shirt sales, as well as an annual walk to raise funding to support ongoing services. MDHHS brings attention to these activities by issuing press releases and working with the Governor's office to issue proclamations during

these key health observances and events. Altogether, 27 special events have been implemented since 2015. Each of these events brings awareness to these serious chronic conditions and their impact on people of color.

Since the last strategic plan, at least 13 educational sessions and webinars have been developed. SCDA-MI continues to offer their “Sickle Cell 101 and 102” curriculums to provide basic information about the disease to families with children who are newly diagnosed. These sessions were provided in-person until the COVID-19 pandemic, when sessions were moved to a virtual platform. The SCDA-MI now offers a series of YouTube videos, which patients and parents can access at their convenience.

MDHHS, in partnership with SCDA-MI and the MPHI Learning Collaborative, created a web-based training module titled [“Sickle Cell Disease: Pain Management Education Online Course for Health Care Professionals.”](#) Recordings of live conference sessions and the development of webinars that offer nursing contact hours are also used to increase knowledge and/or promote the adoption of evidence-based recommendations for the management and care of individuals with SCD.

SCDA-MI's CEO, Dr. Wanda Whitten-Shurney, along with other team members, virtually engaged with hospital staff during Grand Rounds, clinic staff based in Federally Qualified Health Centers (FQHCs), and CSHCS programs within local health departments (LHDs) to promote awareness and share knowledge.

Central to all these efforts are collaborations. Some of these have existed for years, while others have sprung forth because of new opportunities. Two examples of the latter are the [Midwest Genetic Network \(MGN\)](#) and [Sickle Treatment and Outcomes Research in the Midwest \(STORM\)](#) regional projects.

The MGN is one of seven federally funded regional genetic networks. It unites patients, families, geneticists, genetic professionals, primary care providers (PCPs), payers and public health experts from seven states to improve equity in access to genetic services for medically underserved populations. The seven states in the MGN region are Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio, and Wisconsin. While the focus of the MGN is broad, both geographically and in the number of conditions about which it provides education, their contributions to SCD efforts in Michigan have been meaningful. Michigan families with children who have SCD receive assistance in finding genetic counselors, as well as participate in educational programming to learn about the benefits of care coordination services.

Multiple MDHHS programs are engaged with the MGN, such as CSHCS Family Center, PHG and NBS, to serve children and families with complex medical needs

from diagnosis and through every stage of their health care journey. As a result of these collaborations, MGN has developed frequently asked questions (FAQs), handouts, and videos specific to SCD and SCT which are shared on various websites.

STORM has also worked to improve the quality of life and health outcomes for Midwesterners with SCD through its learning collaborative of health professionals. For nearly a decade, this collaborative has focused on quality improvement projects and provider education. By working with pediatric and hematology practices, STORM is building a functional, sustainable, and synergistic network that improves both outcomes and care.

Lastly, in a broad move to address implicit biases in health care settings, the Public Health Code – General Rules was modified in 2020 per [Executive Directive 2020-07](#). The rule (updated in March 2023) requires all licensed health care professionals to complete implicit bias training for initial licensure and renewals ([see FAQs for Implicit Bias Training, LARA, March, 2023](#)). Effective June 2022, these mandated trainings assist health care workers with learning how to recognize and mitigate implicit bias in their encounters, leading to improved equity in the delivery of health care services and a reduction in disparities in health outcomes.

Websites, Apps, and Listservs Created and/or Updated:

- ✓ The SCDA-MI updated its [website](#) to improve awareness and access to educational materials and to better promote its services to patients with SCD and their families.
- ✓ The [Michigan Hemoglobinopathy Quality Improvement Program \(HemQIP\)](#) website was developed to provide information about SCD and create an awareness of how Michigan is working to address this health condition.
- ✓ The [Michigan Sickle Cell Data Collection](#) website was developed to make Michigan specific data available to the public, health care providers, and key community partners to inform them of best practices, improve access to care, and to promote new resources.
- ✓ The Midwest Genetics Network released the [Journey Through Diagnosis](#) web app — a tool designed for families of a child with a genetic condition to assist them in learning more about their child's condition from other families who are on the same journey.
- ✓ MDHHS distributes quarterly updates to a listserv of over 150 interested health care professionals to ensure they remain knowledgeable and aware of best practices, training opportunities, and evidence-based tools that have been released.

- ✓ McLaren Health Plan developed a website to promote their own [Sickle Cell Program](#), a comprehensive program that emphasizes self-management, follow-up, medication adherence and preventive screenings. It was designed specifically for their beneficiaries who have been diagnosed with SCD.

Educational Materials Developed:

- ✓ SCDA-MI developed a [Hydroxyurea FAQ](#) to answer patient questions about this treatment option.
- ✓ MGN and UM jointly developed a [Sickle Cell Trait: What You Need to Know FAQ](#), which has been posted on multiple websites.
- ✓ SCDA-MI's SCT newborn screening (NBS) notification letter was updated to focus on the critical need to know one's status when making informed reproductive health decisions. The letter is distributed to families and PCPs as a part of NBS follow-up.
- ✓ SCDA-MI developed the [SAFER](#) wallet card for patients and caregivers to share with emergency room physicians when experiencing a pain crisis. The card provides easy access to evidence-based clinical guidelines, treatment protocols, and educational resources.
- ✓ MDHHS developed the following resources which were posted to its website: [A Quick Look at Vaccines Needed for Persons with SCD](#); [an SCD Fact Sheet](#), and [a SCT Fact Sheet](#).
- ✓ MDHHS developed the [Sickle Cell Disease Partners Call to Action](#) resource that outlines key strategies for addressing SCD challenges, needs, and issues within Michigan.
- ✓ MDHHS and the Michigan Department of Education (MDE) collaborated to develop and release a [Sickle Cell Toolkit: Supporting Students with Sickle Cell Disease in School Standards of Care](#), which includes training standards for school personnel to assist them in caring for students with sickle cell disease.

Proclamations Issued or Events:

- ✓ Newborn Screening Awareness Month, September 2019.
- ✓ Sickle Cell Day in Michigan, June 2021.
- ✓ Sickle Cell Day in Michigan, June 2022.
- ✓ Sickle Cell Awareness Day in Michigan, June 2023.
- ✓ Sickle Cell Awareness Day in Michigan, June 2024.
- ✓ SCDA-MI annual promotion of World Sickle Cell Day on Juneteenth and t-shirt sales, has occurred annually since 2015.
- ✓ SCDA-MI annual sponsorship of the Sickle Cell Matters Walk – a celebration of Sickle Cell Awareness Month (focuses on a different aspect of the disease each year) occurs annually in September since 2015.

- ✓ [Michigan Raising Awareness of Sickle Cell Disease, Sickle Cell Trait](#), September 2014.

Educational Sessions and Webinars:

- ✓ SCDA-MI developed two training sessions: Sickle Cell 101 and 102. Newly diagnosed patients and their families can attend these sessions to learn more about how to manage their disease.
- ✓ SCDA-MI posted a YouTube video: [“Questions about Hydroxyurea”](#) to answer frequently asked questions about this treatment option. Additionally, Dr. Wanda Whitten-Shurney has been very active in educating health care professionals, speaking at grand round sessions sponsored by various health care systems, presenting to staff at FQHCs and serving as a guest presenter at the Home Visiting Conference on two separate occasions.
- ✓ MGN, working in partnership with UM, posted the video: [“Pediatric Sickle Cell Improvement Program \(P-SCIP\) – Ask the Expert”](#) to educate providers about sickle cell treatment and care management.
- ✓ MGN, working in partnership with UM, posted the video: [“Pediatric Sickle Cell Improvement Program \(P-SCIP\) – Incentives”](#) to promote and educate providers on how to incentivize patients and families in their care maintenance.
- ✓ MDHHS and MDE collaborated to offer a session titled “SCD Standards of Care for School Personnel” at the 2023 MI School Nurse Summer Institute.
- ✓ MDHHS collaborated with HemQIC to develop and post [Sickle Cell Pain Management Educational Webinar for Health Care Professionals](#). Course completion awards 1.5 nursing contact hours.
- ✓ CSHCS sponsored two parent mentor trainings specific to SCD in 2021 and 2024.
- ✓ CSHCS recruited one parent mentor who is paired with parents of newly diagnosed children with SCD to help them learn more about the system of care.
- ✓ CSHCS focused its [2022 Annual Meeting](#) on SCD education. The training targeted local program staff from all 45 LHDs, as well as staff and representatives from Medicaid Health Plans (MHPs).

Collaborations/Partnerships:

- ✓ SCDA-MI and local providers participate in STORM, the regional learning collaborative, to access and utilize various patient/parent decision-making tools, which they can adapt for their own purposes.
- ✓ SCDA-MI worked with Diplomat Pharmacy to develop patient education materials for distribution to those with SCD.
- ✓ Formation of the MGN – Region 4, a seven-state learning collaborative, to unite patients, families, geneticists, genetics professionals, PCPs, payers, and public

health experts to improve equity in access to genetic services for medically underserved populations.

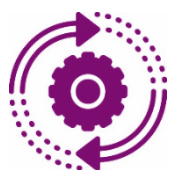
- MGN worked with Paula Tanabe, Ph.D. to modify the adult Emergency Department Sickle Cell Assessment of Needs framework for use with pediatric patients.
- ✓ Ongoing utilization of the HemQIC to inform NBS programming, foster best practices, and promote evidence-based strategies for the care and treatment of SCD among Michigan's hematologists.
- ✓ The joint submission of a legislative funding request proposal by CSHCS and PHG to improve health insurance adequacy for adults with SCD through the CSHCS sickle cell expansion efforts. Additionally, this proposal helped to ensure adequate funding for SCDA-MI for future years and provided funds for the expansion and enhancement of Michigan-based SCD clinics.

Implicit Bias Training:

- ✓ Implicit bias training requirements for health care professionals were incorporated into the state's licensure process in June 2022. Health care professionals must provide proof of training when applying for or renewing their license. The Department of Licensing and Regulatory Affairs (LARA) oversees both the approval of the implicit training programs available, as well as health professional completion verifications. These efforts benefit those with SCD and their caregivers by addressing health disparities and inequities encountered within health care settings.

GOAL 2: TRANSITION

To develop and implement strategies for improving the transition from pediatric to adult care.



The American Society of Hematology (ASH) reports that over the past four decades, technological advancements, combined with increased use of disease-modifying therapies, have contributed to decreased mortality rates associated with SCD across the lifespan. Although overall mortality has decreased, this decline has not been observed uniformly across all age groups. According to ASH, “This overall improvement [in life expectancy], provides contrast to the enduring sharp increase in mortality in the young adult years. This demonstrates the critical need to improve the transition process from pediatric to adult care and to emphasize the need for additional support for young adults after they transition to adult SCD care.”⁴

When young adults with SCD transfer their medical and non-medical care to adult services, they may feel uncomfortable and find it difficult to understand all that is

expected of them, including the need to find new doctors, and navigate health insurance systems. A new emphasis on providing the necessary information and resources to help youth transition into the adult care setting was a priority of the 2015 Strategic Plan. Such initiatives were deemed as valuable — not only to public health programs - but also to hematologists and PCPs who need to manage patient care in tandem with pediatric specialists to ensure successful transition. Given the importance of transition, the strategic plan focused its efforts on a single strategy:

Strategy 1: Increase resources and tools for specialty care clinics, community-based organizations/clinics, and health care providers to utilize, in order to systematically enhance the transition process for patients.

Many of the tactics identified within this strategy were tasked to CSHCS at MDHHS. For more than a decade, CSHCS has led efforts to improve the [pediatric to adult health care transition](#) for children and youth with special health care needs. Using a mix of state and federal resources, CSHCS has improved transition services, offered training to LHD staff providing locally based CSHCS case management and care coordination services, incorporated transition planning requirements into Medicaid health plan agreements, and ensured that transition services are offered by CSHCS Children's Multi-Disciplinary Specialty (CMDs) clinics. While many of these efforts focus on the broader topic of transition for children and youth with special health care needs (CYSHCN), patients with SCD and their caregivers represent a segment of this population and benefit from CSHCS' efforts. Additionally, both MGN and [Michigan Family to Family](#) have contributed by posting transition resources for persons with SCD and their families to their respective web pages.

This section of the report provides a high-level overview of some of the most important activities developed and/or implemented that directly impact clients with SCD. It does not capture all efforts, as some are difficult to quantify.

Policy-Related Initiatives:

- ✓ CSHCS established a permanent transition specialist position within its program to assist providers, LHDs, and CSHCS families in learning about transition services and accessing transition resources.
- ✓ CSHCS incorporated transition planning into its Maternal Child Health Plan, establishing annual goals, priorities, activities, and monitoring indicators to help improve transition services for all its beneficiaries.
- ✓ CSHCS required MHPs to have a written and approved transition policy, as outlined in the MHP contracts. Additionally, MHPs must use appropriate tools

and resources when working with CSHCS enrollees and families to ensure health care transition from pediatric to adult providers.

- ✓ CSHCS established indicators and minimum program requirements related to pediatric to adult transition services within the CSHCS section of the Michigan Local Public Health Accreditation Program.
- ✓ Transition service indicators were established as a component of the CMDs clinic site reviews, thus securing the provision of transition services from pediatric to adult care as a mainstay of this enhanced care coordination program.
- ✓ CSHCS initiated the Assessment of Health Care Transition surveys with LHDs and MHPs on an annual basis. This quality improvement tool, developed by GotTransition®, helps organizations to assess their current status and identify areas for improvement, along a transition service continuum.

Resource Development:

- ✓ CSHCS developed a transition toolkit for Children and Adolescent Health Centers (CAHC) to assist them in working with students and families in accessing transition services.
- ✓ CSHCS created a [transition website](#) and posted a variety of tools. These tools are divided into four categories: Youth & Young Adults; Parents, Caregivers, and Families; Health Care Teams (i.e., providers, LHDs and MHPs), and Resources.
- ✓ Michigan Family to Family compiled a [list of family resources](#) and posted them on their website, including a webpage devoted to transition.

Educational/Awareness Efforts:

- ✓ CSHCS focused on health care transition as the topic of the Fiscal Year (FY) 2017 CSHCS Annual Meeting, bringing state experts in health care transitions to train LHDs.
- ✓ CSHCS held a transition session as part of the FY 2022 CSHCS Annual Meeting, which focused on SCD.
- ✓ CSHCS implemented a process to send automated transition letters to clients at specific age intervals to assist parents and caregivers in understanding and planning for important transition milestones across the lifespan of their child.
- ✓ PHG distributed regular updates to a MDHHS maintained listserv of more than 150 SCD Michigan-based providers to assure they remain knowledgeable about innovative and evidence-based resources on health care transition and other topics.

Collaborations/Partnerships:

- ✓ CSHCS established an internal collaborative body that consisted of representatives from CSHCS, Office of Medical Affairs, and PHG to develop the transition letter series.
- ✓ CSHCS formed relationships with the MDHHS CAHC program and the nationally recognized Got Transition® program to pilot a school-based clinic transition program, which resulted in the creation of a transition toolkit.
- ✓ CSHCS participated in the [Michigan Interagency Transition Team \(MITT\)](#), a 21-state agency collaboration formed for the purpose of promoting integrated transition services and evidence-based practices to children and young adults with disabilities.
- ✓ Transition was selected as one of the possible funding strategies for the Sickle Cell Clinical Expansion and Enhancement (SCCEE) grants and has been a focus of two SCCEE-funded projects at Michigan State University (MSU) and Henry Ford Health (HFH).
 - MSU was working to develop and implement a transition program within its SCD Lifespan Clinic. (2022-2025)
 - HFH and Children's Hospital of Michigan (CHM), both located in Detroit, are working together to implement a collaborative transition process to ensure that patients approaching adulthood are appropriately transitioned from the CHM pediatric hematology clinic to the adult SCD clinic at HFH. (2022 and ongoing)

GOAL 3: PROVIDER SHORTAGE

To increase the availability of providers who treat all aspects of SCD with an emphasis on increasing providers for adults.



Despite innovations in medical care which have led to improved life expectancy among individuals with SCD, clinical management for the condition continues to pose substantial challenges for patients, families, and providers. SCD requires a significant commitment of medical resources including pediatric and adult hematology, nursing, and other specialists. National studies show an increase in the morbidity rate after transitioning to adult care due, at least in part, to a lack of comprehensive programs for adults with SCD.⁵ In Michigan, there has been a clear lack of adult providers for either primary or specialty/subspecialty care. Prior to the 2015 SCD Strategic Plan, there was only one clinic in Detroit devoted to treating adult patients with SCD, and it was unclear where remaining adult patients went to receive care. To address this issue, a comprehensive strategy was formulated to mitigate the burdens borne by patients and health care systems as a result of persistent provider shortages.

Strategy 1: Increase the number of providers caring for patients with SCD in Michigan.

According to the American Association of Medical Colleges (AAMC), in 2021 Michigan ranked 15th among the states for total active patient care PCPs, with a rate of 90.6 active PCPs per 100,000 patients.⁶ This rate was similar when compared to 2015 data, which reported a rate of 88.4 per 100,000 patients.⁷ Despite these rankings, 73 of Michigan's 83 counties have been designated by the Health Resources and Services Administration (HRSA) as containing either a population group or geographical-based health professional shortage area⁸. These trends have contributed to patient difficulties in obtaining appropriate primary care from knowledgeable and competent health professionals.

Furthermore, the [AAMC U.S. Physician Workforce Data Dashboard](#) (2023) indicates that Michigan is home to approximately 600 hematologists and oncologists, including both adult and pediatric subspecialists⁹. Data from the state's Medicaid electronic claims system (the Community Health Automated Medicaid Claims Processing System - CHAMPS) for calendar year 2024 estimates that only 30% of its active hematologists were treating patients with a SCD diagnosis.

To address the lack of health professionals and the access to care issues that result, several activities have been implemented to improve the adequacy of health insurance, and the quality and availability of clinical services.

Adequacy of Health Insurance:

- ✓ In FY 2020, MDHHS proposed expanding CSHCS eligibility across the lifespan for those diagnosed with SCD. This proposal was adopted, and its funding was included in the FY 2022 budget appropriation bill.
 - FY 2021, the Michigan Legislature approved the recommended \$6.65 million appropriation as requested as part of the MDHHS FY 2022 budget package and the Governor signed the legislation into law in September 2022.
 - In October 2022, CSHCS expanded its eligibility to cover individuals with SCD, regardless of age, ensuring that people with this rare blood disorder received the same level of benefits previously available only to those with hemophilia and cystic fibrosis.
 - CSHCS contacted past program recipients who were enrolled in CSHCS due to their SCD diagnoses to inform them of the program's expansion. They also contacted other community partners, including SCDA-MI, LHDs, providers, MHPs, and the community, to inform them of this age expansion opportunity.
 - Since FY 2022, CSHCS has enrolled nearly 600 individuals with SCD who are over the age of 21 years.

- ✓ Michigan Medicaid, working collaboratively with PHG, responded to a request for applications to participate in the Centers of Medicare and Medicaid Services' (CMS) new Cell and Gene Therapy (CGT) Access Model. This voluntary, multi-year program aims to improve the lives of people with Medicaid living with rare and severe diseases by increasing access to potentially transformative treatments. The model's initial focus is on expanding access to cell and gene therapies for SCD. Michigan's participation in the program is expected to start during 2025.
- ✓ The UM CHEAR Center, in collaboration with MDHHS' Managed Care Plan Division, has implemented P-SCIP through selected MHPs. Through this program, MHPs are financially incentivized to improve the quality of care for their pediatric patients with SCD. The project focuses on three key areas for improvement: antibiotic prophylaxis use, hydroxyurea use, and transcranial doppler screenings. The program is entering its fifth year and has produced promising results.

Clinical Care Initiatives:

- ✓ House Bill 4603, 2014 (Senator Jim Ananich) – This bill did not pass, but it was the department's first opportunity to obtain funding through legislation. A bill analysis was drafted. The bill requested funding to support:
 - A Michigan Department of Community Health (prior to the merger that created MDHHS) and Detroit Medical Center (DMC) collaboration to establish a one-year fellowship program (requested: \$200,000);
 - Employment of five part-time nurse practitioner/social worker positions across clinical sites (requested: \$250,000);
 - Two 24-hour hospital day clinics (requested: \$240,000); and
 - Employment of patient navigators to assist with transition (requested: \$120,000).
- ✓ In FY 2022 and FY 2023, the SCDA-MI was awarded a combined total of \$5 million in legislative funds to oversee the establishment of a SCD Center of Excellence (CoE) to be located in the City of Detroit, where over 60% of Michigan patients with SCD reside. (MiSCDC, 2025). The following activities have been accomplished and/or are in process:
 - SCDA-MI entered into an agreement with HFH to establish the proposed CoE, which is called the [Henry Ford Comprehensive Adult Sickle Cell Center](#).
 - Per that agreement, HFH developed and is implementing a business plan to ensure ongoing sustainability of the comprehensive adult clinic.
 - HFH has assembled a multidisciplinary team and formed a SCD clinic unit within its health care organization. Staff include: hematologists/physicians,

nurse practitioners, a social worker, a registered nurse, a dietitian, and other necessary ancillary and auxiliary staff/services to support a comprehensive SCD treatment program that serves as a medical home for a growing caseload of 150 to 200 patients with SCD. Caseload growth is expected to surpass 500 patients in the next two to three years.

- HFH has purchased medical equipment and clinical space (i.e., apheresis machines, infusion space, etc.).
 - HFH has begun renovation of clinic space on their main Detroit campus to house the new SCD comprehensive center.
 - HFH SCD Comprehensive Adult Sickle Cell Center is participating in national clinical trials and is developing capacities to offer new CGT treatments to eligible clients seeking those options.
- ✓ In addition to the CSHCS age expansion, the legislatively funded joint proposal submitted by CSHCS and PHG included approximately \$400,000 in additional funding to support SCCEE projects, as well as the administration of those funds. Requests for proposals were released in January 2022 and April 2023, which resulted in the funding of five Medicaid administrative (50%/50%) matchable projects. Awarded grant project descriptions are as follows:
- HFH's project focused on assuring a smooth transition of patients with SCD from pediatric to adult care, as well as improving access to other specialty and treatment management services, such as orthopedics, pain management and allied health services.
 - MSU's project established a Sickle Cell Disease Lifespan Clinic in Lansing within its Inherited Blood Disorder Service. This clinic was staffed by a multidisciplinary team and was available to both pediatric and adult patients up to age 26. (Project ended in June 2025).
 - UM's SCD project focused on quality improvement and sought to ensure health care providers followed national guidelines and patients and caregivers practiced preventative care, including keeping appointments and following disease-altering treatments and medication recommendations.
 - CHM, through its Better Radiology Access to Improve Neurological Outcomes (BRAIN) project, sought to reduce the incidence of stroke among its pediatric patients with SCD by improving access to necessary transcranial doppler ultrasounds.
 - Bronson Health Foundation addressed access to care and quality by developing improved referral networks and implementing a sickle cell-specific data collection module in their electronic medical record system. It also worked to increase SCD education among its providers and improve pain management protocols within its emergency department.

- ✓ UM received seed funding to establish an adult SCD clinic. This clinic helps to ensure the smooth transition of care for patients currently seen at its pediatric SCD clinic.

Telemedicine/Telehealth:

- ✓ Several policy initiatives and laws related to telemedicine have been adopted since the release of the 2015 SCD Strategic Plan, which provides a strong foundation for expanding and enhancing access to care for patients. These standards and requirements significantly impact the ease and use of medical care delivery via telemedicine, including but not limited to: Parity Law for Commercial Payers; online prescribing; and telemedicine services with originating sites in-home and/or in-school settings.
 - Additionally, Michigan's Medicaid policy allows for reimbursement of telemedicine services, when provided in accordance with state and federal mandates.
- ✓ Michigan-based providers and the SCDA-MI maintain their participation in STORM, a regional sickle cell telehealth network, funded by a [HRSA Treatment Demonstration Project](#). The TeleEcho initiative seeks to improve outcomes for individuals with SCD living in Indiana, Illinois, Michigan, Minnesota, Ohio, and Wisconsin. The goal of the STORM network is to increase the number of pediatric and adult PCPs who are knowledgeable about the management and treatment of SCD, and who are willing to prescribe and manage hydroxyurea therapy to improve medical care for the approximately 15,000 individuals living with SCD in the Midwest.
 - As part of STORM, Michigan participated in [Project ECHO™](#) (Extension for Community Healthcare Outcomes) a telementoring model, which used low-cost video technology to link expert interdisciplinary specialist teams with primary care providers to improve management of chronic diseases.
 - Michigan STORM partners hosted two continuing medical education (CME) dinners for health care providers on the management of SCD and the use of hydroxyurea with over 35 attendees.
 - Michigan STORM partners collaborated with the Michigan Primary Care Association, which serves 39 Michigan health center organizations, to plan and host SCD Lunch and Learns for providers in health centers with higher populations of patients with SCD.
 - Michigan STORM participants provided Medicaid claims data to the National Institute for Children's Health Quality (NICHQ) in response to their Call for Data.

GOAL 4: PSYCHOSOCIAL/MENTAL HEALTH

To increase recognition of the need to address psychological issues and provide mental health support for individuals living with SCD and their families.



Psychological complications in patients with SCD mainly result from the impact of pain and symptoms on their daily lives, as well as society's attitudes towards them. Studies have shown that the most frequent psychological complications and challenges encountered include increased anxiety, depression, social withdrawal, aggression, poor relationships, and poor school performance.¹⁰ A few case reports also identified high levels of parental anxiety, overprotection, excessive feelings of responsibility and guilt. These issues are made more difficult because of the social, economic, and health care disparities experienced by many people with SCD. To tackle this issue, adequate psychological support was identified as a strategy to improve an individual's quality of life. Appropriate assessments of psychological factors are also needed.

Strategy 1: Increase partnerships and resources for mental and behavioral health providers to decrease rates of psychiatric morbidity in the SCD population.

Since 2015, Michigan has implemented significant changes in the state's mental and behavioral health care system to improve access to services, including:

- ✓ Establishment of additional managed care mental health benefits for Medicaid beneficiaries enrolled in MHPs;
- ✓ Implementation of opioid health homes to provide care to people struggling with addictions to prescription pain medications; and
- ✓ Initiation of certified community behavioral health clinics, which provide mental health, primary care, rehab services, targeted case management, and crisis support to qualified beneficiaries.

While these programs are not specific to clients with SCD, they represent improvements in a system of care that serves clients who have dual medical and behavioral health diagnoses, which can include people with SCD.

In addition, the CSHCS program with its focus on case management and care coordination services, has implemented multiple approaches to ensure that families can access needed care, including medical, educational, mental health, and community-based services. One approach used for improving access to care is the CMDS program. This program offers a highly coordinated, interdisciplinary approach for the management of specified complex medical diagnoses. CMDS clinic staffing requires, at a minimum, a physician/specialist, registered nurse, social

worker, and dietician. Together, these professionals form a multi-disciplinary team with the client/caregiver to complete an assessment and develop an individualized plan of care. Clinic staff also provide support to clients/caregivers in accessing a variety of psychosocial services. This service represents a more intensive level of case management and care coordination than one would receive from a standard clinic. CMDS clinics are housed in tertiary care hospitals and receive enhanced reimbursement for their services. SCD is one of 22 medical conditions for which CMDS clinics currently exist.

CSHCS also provides case management and care coordination services through its network of LHDs. Nurses and local service representatives at Michigan's 45 LHDs assist beneficiaries with CSHCS coverage to access transportation and translation services, coordinate insurance benefits, obtain community resources, and learn self-advocacy skills.

CMDS Clinic Services at Participating Hospitals:

- ✓ Since 2015, seven CMDS clinics have been established and are providing both treatment and care coordination services to patients with SCD. In FY 2024, there were 295 paid encounters delivered through CMDS clinics to patients with a SCD diagnosis(es). When compared to the previous year, this represented more than a 50% growth in visits. Due to time lags associated with billing delays, 2025 CMDS encounter numbers are not available; however, these numbers are expected to continue to grow.

Local Health Departments:

- ✓ During FY 2024, LHDs served 109 clients who had a SCD diagnosis, providing 246 case management and care coordination services, according to the CSHCS' Children's Healthcare Automated Support Services (CHASS) data system. More than 50% of these services were delivered in the Greater Detroit Area.
 - LHDs delivered 2 case management services to clients with SCD. These services included face-to-face encounters, usually in the home setting, where nurses worked with clients to complete patient assessments and integrated plans of care.
 - LHDs delivered 55 care coordination level I services, which included client-specific, comprehensive care/service plans developed by a registered nurse or licensed social worker in partnership with the family and/or client.
 - LHDs delivered 189 care coordination level II services, which consisted of interactions with the family/client and CSHCS staff involved in the care of the client by telephone, in-person, or in writing. Level II activities include, but are not limited to, arranging for service delivery from CSHCS-qualified providers,

advocating on behalf of clients, assisting with social, educational, or other support services, facilitating transitions, assisting clients moving into or out of MHPs, and assisting with applications for the [Children with Special Needs \(CSN\) Fund](#).

Other Psychosocial Initiatives:

- ✓ As part of their MDHHS agreement for newborn screening coordination, SCDA-MI financially supports a full-time social worker at CHM, as well as a portion of a full-time psychologist.
- ✓ SCDA-MI community outreach workers and patient advocates provide public health education, social work, and care coordination services to those with SCD at CHM, as well as through their main office in Detroit and satellite offices located in Lansing, Saginaw, Benton Harbor and Grand Rapids. Services also include trait follow-up and psychosocial assessments for families of clients with SCD.
- ✓ As part of the services provided by SCDA-MI, clients are asked to complete an annual psychosocial inventory called the Health Status Assessment (HSA). Between 2013 and 2024, 1,791 HSAs had been collected, 1,283 as initial HSAs and 508 as follow-up HSAs. From the initial HSAs, the following sampling of key information was gathered:
 - One in four with SCD in Michigan reported they experienced transportation insecurity for medical appointments. Their personal car was the most frequent mode of transportation available for routine medical appointments.
 - Of individuals over 18, 47.6% reported that their employment had been impacted by SCD.
 - Among children 5-18 years, caregivers reported that 22.7% had an Individualized Education Program (IEP) in place; 13.0% had a 504 plan in place which guarantees individuals with disabilities have equal access to education; and 4.6% had both an IEP and 504 plan in place.
- ✓ In FY 2025, Greater Flint Area Health Coalition acquired the Flint Area Nurse Navigator Program for patients with SCD. The program, which originally was operated through Hurley Hospital, provides services for over 25 high-risk patients with SCD (i.e., clients who meet or surpass thresholds for ED visits and/or hospital admissions due to pain crises) and reside in the Flint area. With the help of a hematologist and registered nurse, the program is designed to increase patient medical literacy, and improve self-care skills and medication adherence, as well as render emotional support to program participants.
- ✓ Over the last year, the hematology clinic at Bronson Children's Hospital has expanded its psychosocial efforts to support patients with SCD. The goal was to

create a forum and space for parents who have children treated within the clinic to connect and support one another.

- The Bronson team planned in-person and virtual support groups, which were facilitated by the nurse educator and a selected parent leader.
- Recently, the team developed a Facebook page where parents can connect more informally and frequently about their care and treatment experiences.
- Outside of the parent-support efforts, Bronson has continued to support strong relationship building with families by providing educational bags and binders to all families. They also provide the Sickie Cell Story Club. The Story Club provides books to children at each clinic visit and daily during hospital admissions that have a main character that looks like them. The goal of the Story Club is simply to build relationships, trust, and literacy. Since its inception, the Story Club has provided approximately 450 books to children attending Bronson Children's Hospital SCD clinics.

GOAL 5: MEDICATION ADHERENCE

To develop protocols for improving medication adherence in accordance with the NHLBI Evidenced-Based Management of SCD Guidelines.



In Michigan, it is mandatory to screen every newborn for SCD to facilitate the start of prophylactic penicillin and anticipatory guidance prior to four months of age. In addition to daily administration of penicillin until at least five years of age, children and adults with SCD often require other daily medications such as folic acid, hydroxyurea, and oral iron chelation therapy to decrease the risk of complications. Given the high expectation of this patient population to take daily medications to prevent complications of the disease, understanding and improving the rate of medication adherence is an important component of patient care. The following strategy was identified for this goal.

Strategy 1: Increase understanding of patient motivating factors for medication adherence.

While several SCCEE projects address ways to improve medication adherence for patients with SCD, a variety of approaches have been taken. For many of the projects, collaborating with the MiSCDC program and sharing patient information with them for the purpose of public health surveillance ensures a ready source of accurate data for on-going monitoring of medication adherence at the clinic level. As an example, given MiSCDC's ability to access limited datasets, including the MDHHS data warehouse, participating clinics can now receive information about the number of prescriptions filled and the frequency of their refills for their Medicaid patient population. With appropriate data use agreements and institutional review

board approvals in place, this data sharing assists clinicians in designing and implementing quality improvement projects that improve patient medication adherence.

Additionally, two MDHHS SCCEE funded projects have included quality improvement initiatives associated with medication adherence. Bronson Health Foundation has implemented a SCD module within their Epic medical records system to facilitate the monitoring and reporting of patient medication adherence, as well as other patient outcomes, for their patients with SCD.

Secondly, UM's Pediatric Sickle Cell Clinic has chosen to focus completely on quality improvement, using a two-prong approach to improve medication adherence. Record reviews were conducted to ensure that providers were adhering to NHLBI Evidenced-Based Management of SCD Guidelines. Also, researchers engaged clients through a series of interviews and focus groups to learn about challenges patients face in adhering to recommended hydroxyurea protocols and dosing. Based upon their findings, they are developing educational interventions and implementing a series of Plan, Do, Study, Act (PDSA) cycles, which are designed to address patient identified issues.

Monitoring:

- ✓ Several indicators are tracked by MiSCDC, including:
 - Antibiotic Prophylaxis – prescriptions filled and average daily supply.
 - Immunization adherence – completion rates for primary immunizations, receipt of annual flu vaccine, receipt of at least one COVID-19 vaccine.
 - Hydroxyurea – prescriptions filled and average daily supply.
- ✓ Beginning in 2023, four of the seven MDHHS SCD-funded projects are currently participating in the MiSCDC where they share client information and receive data to assist them with monitoring their clinic population's progress in adhering to medication regimes.
- ✓ UM Pediatric Sickle Cell Clinic reported the following outcomes for their QI project in 2024:
 - Completed interviews with 90% of clinic patients who were seen and prescribed hydroxyurea to better understand patient barriers to successful use of this medication.
 - Approximately one-third of the patients prescribed hydroxyurea, along with their caregivers, have participated in an educational/counseling session about the importance of medication adherence and have received advice on how to work with their child to improve compliance.

- A draft decision aid has been developed which explains potential benefits and downsides of treatments. Use of this aid promotes conversation between the patient/family and provider helps to ensure joint decision-making occurs.

GOAL 6: DAY TREATMENT CLINICS

To improve acute care in the emergency room or alternative settings.



Recurrent episodes of pain are the most consistent expression of SCD. Pain management involves taking care of both acute and chronic pain.

One intervention that has improved the care of patients with SCD is the institution of a day treatment clinic where acute episodes of pain can be managed without resorting to emergency room care. Day treatment clinics offer many advantages:

1. Most patients return home the same day.
2. Treatment can begin within minutes of arrival.
3. Staff may be familiar with the patients and their analgesic requirements for pain control.
4. Hospitalizations and ED visits are reduced.
5. Cost of care decreases.

To address the need for day treatment centers (given that none existed in Michigan at that time) the following strategy was adopted:

Strategy 1: Partner with hospital systems to promote opportunities, training, and best practices to increase patient satisfaction in the emergency room or alternative settings.

A legislative proposal to establish a SCD day treatment program was formulated in 2014. This program, which was designed to serve as an alternative to the traditional hospital ED, was to be accessible 24 hours a day, seven days a week; and would offer prompt, aggressive treatment of acute pain crises. According to the literature,¹¹ similar programs have demonstrated:

1. Better pain management, with treatment delivered, on average, in less than half the time of an ED visit.
2. Cost savings; and,
3. Better treatment delivered by staff trained and experienced in SCD pain management approaches.

The proposal recommended two clinics — one at DMC and the other at Hurley Hospital, Flint — to be established with an estimated cost of \$240,000 per site per year. Clinics were to be staffed by a practitioner/physician assistant, registered

nurse and have available physician back-up, as needed. Unfortunately, the legislation did not advance; however, it did lay the groundwork for both the establishment of the proposed CoE for SCD and the SCCEE Clinics which were funded in FY 2022.

Clinical Projects:

- ✓ HFH, with a portion of its SCCEE funding, is improving access to infusion services. Currently, HFH patients with SCD can be seen at four centers to receive parenteral opioids and/or hydration infusion services.
- ✓ HFH, as part of their CoE funding, has purchased two apheresis machines to regulate iron levels, assist with oxygen capacity, and reduce vaso-occlusion complications in patients with SCD. The comprehensive adult clinic will make apheresis services available in FY 2025.
- ✓ HFH has incorporated a comprehensive pain clinic and an acute care clinic into its comprehensive adult clinic model, as alternatives to ED visits and hospitalizations.

GOAL 7: RESEARCH

To establish a Michigan SCD Consortium to coordinate public health research efforts in Michigan.



Over the past several decades, scientists and doctors have learned a great deal about SCD. They know its cause, how it affects the body, and how to treat many of its complications. Thanks to improved treatment and care, people who have SCD are now living into their 40s, 50s or beyond. To this end, a need was identified to establish and/or expand various advisory groups to include leading hematologists, public health professionals, people with SCD and their families, and academia, who would work together to find solutions to many of the problems posed by SCD. A growing interest in research opportunities that were designed to inform medical, education, and policy-related initiatives, led to the adoption of the following strategy:

Strategy 1: Increase public health capacity to facilitate research opportunities in Michigan.

Because of the Center for Disease Control and Prevention's (CDC) funding opportunities and the department's strong partnership with the UM CHEAR Center, Michigan has excelled in the area of collaborative public health research through the establishment of the [MiSCDC program](#).

In 2019, MDHHS received a one-year CDC-funded cooperative agreement to plan a statewide SCD surveillance program. Subsequently, it was determined that the UM

CHEAR Center had the expertise and capacity needed to lead this effort. MiSCDC began in October 2020 and continues today to address knowledge gaps in SCD and disease management by studying the long-term trends in diagnosis, treatment, and health care access for people with SCD in Michigan. The program helps to inform state policy and health care standards that improve and extend the lives of people with SCD, while also contributing to the national conversation. In addition to working with the Department's SCCEE funded clinics, the program works to access and link multiple data systems with the goal of integrating data sets for improved data mining and public health surveillance. This approach results in increased data quality, better decision-making, and a deeper understanding of program and system gaps and efficiencies.

New information is made available to interested stakeholders through a variety of means, including newsletters, infographics, briefs, and academic literature.

Academic Publications:

- ✓ ["Acute Healthcare Utilization for Individuals With Sickle Cell Disease in Michigan,"](#) 2022 UM Pediatric Research Symposium, May 24, 2022.
- ✓ ["Hospitalization and Mortality due to COVID -19 Among People Born 1987-2019 With Sickle Cell Disease or Sickle Cell Trait in Michigan,"](#) 2022 UM Pediatric Research Symposium, May 24, 2022.
- ✓ ["Sickle Cell Disease: A Case for Racism and Disparities Within Healthcare."](#) 2023 UM Undergraduate Research Symposium, April 7, 2023.
- ✓ ["COVID-19 Immunization Coverage Among Children Living With Sickle Cell Disease in Michigan,"](#) 2023 Pediatric Academic Societies Meeting, April 30, 2023.
- ✓ ["COVID-19 Infection and Outcomes in Newborn Screening Cohorts of Sickle Cell Trait and Sickle Cell Disease in Michigan and Georgia,"](#) Susan T. Paulukonis, Angela Snyder, Matthew P. Smeltzer, Ankit N. Sutaria, Isabel Hurden, Krista Latta, Swathi Chennuri, Elliott Vichinsky, Sarah L. Reeves. Medical Progress, May 2023.
- ✓ ["Case Ascertainment of Sickle Cell Disease Using Surveillance or Single Administrative Database Case Definitions,"](#) Sarah L. Reeves, Sophia Horiuchi, Mei Zhou, Susan Paulukonis, Angela Snyder, Shondelle Wilson-Frederick, Mary Hulihan. Public Health Methodology, May 2023.
- ✓ ["Hospital Utilization by Payer for Youths and Young Adults with Sickle Cell Disease in Michigan,"](#) 2023 UM Pediatric Research Symposium, May 23, 2023.
- ✓ ["Common Data Model for Sickle Cell Disease Surveillance: Considerations and Implications,"](#) Matthew P Smeltzer, Sarah L Reeves, William O Cooper, Brandon K Attell, John J Strouse, Clifford M Takemoto, Julie Kanter, Krista Latta, Allison P Plaxco, Robert L Davis, Daniel Hatch, Camila Reyes, Kevin Dombkowski,

Angela Snyder, Susan Paulukonis, Ashima Singh, Mariam Kayle. JAMIA Open, May 27, 2023.

- ✓ ["State-University Partnership to Implement Public Health Surveillance for Sickle Cell Disease in Michigan,"](#) 2023 Council of State and Territorial Epidemiologists Annual Conference. June 25, 2023.
- ✓ ["Epidemiology of Sickle Cell Disease in Michigan, 2018,"](#) 2023 Council of State and Territorial Epidemiologists Annual Conference, June 25, 2023.
- ✓ ["Use of Telehealth for Individuals With Sickle Cell Disease During the COVID-19 Pandemic,"](#) 2023 Academy Health Annual Research Meeting. June 25, 2023.
- ✓ ["Characterizing Mortality Among Individuals With Sickle Cell Disease in Michigan, 2010 – 2020,"](#) 2023 Council of State and Territorial Epidemiologists Annual Conference, June 25, 2023.
- ✓ ["Examining Community-Level Social Vulnerability and Emergency Department Use for People With Sickle Cell Disease in Michigan,"](#) 2023 Academy Health Annual Research Meeting, June 26, 2023.
- ✓ ["Sickle Cell Disease Births and Social Vulnerability \(2016-2020\): A Report From the Sickle Cell Data Collection Program,"](#) Mariam Kayle, Audrey Blewer, Wei Pan, Jennifer A Rothman, Carri Polick, Joshua Rivenbark, Elliott Fisher, John J Strouse, Shelby Weeks, Jay Desai, Angie Snyder, Mei Zhou, Ankit Sutaria, Sophia Horiuchi, Jhaqueline Valle, Marci K Sontag, Joshua I Miller, Ashima Singh, Mahua Dasgupta, Issac A Janson, Najibah Galadanci, Ayme Miles, Shamaree J Cromartie, Sarah L Reeves, Krista Latta, William O Cooper, Allison Plaxco, Matthew P Smeltzer. 65th ASH Annual Meeting. December 9, 2023.
- ✓ ["COVID-19 Immunization Coverage Among People With Sickle Cell Disease,"](#) Hannah K. Peng, Kevin J. Dombkowski, Melissa A. Plegue, Krista Latta, Ryan Malosh, Melissa S. Creary, Sarah L. Reeves. AMA Network Open, January 8, 2024.
- ✓ ["Birth Prevalence of Sickle Cell Disease and County-Level Social Vulnerability — Sickle Cell Data Collection Program, 11 States, 2016–2020,"](#) Morbidity and Mortality Weekly Report (MMWR), March 28, 2024.
- ✓ ["Assessing Patterns of Telehealth Use Among People with Sickle Cell Disease Enrolled in Medicaid During the Start of the COVID-19 Pandemic,"](#) Sarah L. Reeves, Melissa Plegue, Pooja N. Patel, Susan T. Paulukonis, Sophia S. Horiuchi, Mei Zhou, Brandon K. Attell, Betty S. Pace, Angela B. Snyder, Allison P. Plaxco, Ayesha Mukhopadhyay, Matthew P. Smeltzer, Chandy S. Ellimoottil, and Mary Hulihan. Telemedicine and e-Health. April 11, 2024.
- ✓ ["Epidemiology of Sickle Cell Disease in Michigan, 2020,"](#) 2024 Michigan Public Health Association (MPHA) Annual Epidemiology Conference, April 12, 2024.

- ✓ [“Changes in Hydroxyurea Adherence During the COVID-19 Pandemic Among Children and Young Adults with Sickle Cell Disease.”](#) Pediatric Academic Societies Meeting, May 5, 2024.
- ✓ [“Availability of Transportation to Medical Appointments for Children and Young Adults Living With Sickle Cell Disease in Michigan.”](#) Pediatric Academic Societies Meeting, 2024. May 5, 2024.
- ✓ [“Medicaid Coverage in Early Childhood for Children With Sickle Cell Disease.”](#) Sophia S. Horiuchi, Sarah L. Reeves, Allison P. Plaxco, Hannah K. Peng, Mei Zhou, Mariam Kayle, Mary Hulihan. JAMA Network Open, July 2024.
- ✓ [“Examining Community-Level Social Vulnerability and Emergency Department Use for People Living With Sickle Cell Disease in Michigan.”](#) Jennylee Swallow, Krista Latta, Melissa Plegue, Hannah K. Peng, Renuka Tipirneni, Dominic Smith, Félice Lê-Scherban, Kevin J. Dombkowski, Sarah L. Reeves. Academy Health Annual Research Meeting. June 26, 2023;
- ✓ [“Emergency Department Utilization Before and During the COVID-19 Pandemic Among Individuals With Sickle Cell Disease.”](#) Brandon K. Attell, Allison P. Plaxco, Mei Zhou, Jhaqueline Valle, Sarah L. Reeves, Pooja N. Patel, Krista Latta, Matthew P. Smeltzer & Angela B. Snyder. BioMed Central (BMC) Emergency Medicine. July 29, 2024.

Infographics and Briefs:

- ✓ [Sickle Cell Partners Call to Action](#), November 2021.
- ✓ [SCDC Births 2016-2020](#), July 2022.
- ✓ [Sickle Cell Disease in Michigan](#), July 2022.
- ✓ [State-University Partnership to Enhance Outreach to Adults Living With Sickle Cell Disease in Michigan](#), December 2022.
- ✓ [Michigan Sickle Cell Data Collection Program CDC Site Visit](#), June 2023.
- ✓ [Sickle Cell Disease in Michigan](#), SCDA-MI, September 2023.
- ✓ [Visual Abstract – COVID-19 Immunization Coverage Among People With Sickle Cell Disease](#), February 2024.
- ✓ [“I’ve Lived My Life With Sickle Cell, but Sickle Cell is Not My Life,”](#) Photoblog – Maya, June 2024.
- ✓ [“Turning Pain into Purpose,”](#) Photoblog – Tiffany, June 2024.
- ✓ [Visual Abstract – Assessing Patterns of Telehealth Use Among People With Sickle Cell Disease Enrolled in Medicaid During the State of the COVID-19 Pandemic](#), June 2024.
- ✓ [Success Story – Health Status in Action](#), July 2024.
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- ✓ [MiSCDC Newsletter: October 2022.](#)
- ✓ [CDC SCDC Newsletter: November 2022.](#)
- ✓ [CDC SCDC Newsletter: March 2023.](#)
- ✓ [MiSCDC Newsletter: June 2023.](#)
- ✓ [CDC SCDC Newsletter: July 2023.](#)
- ✓ [MiSCDC Newsletter: December 2023.](#)
- ✓ [CDC SCDC Newsletter: April 2024.](#)
- ✓ [MiSCDC Newsletter: July 2024.](#)
- ✓ [CDC SCDC Newsletter: July 2024.](#)
- ✓ [CDC SCDC Newsletter: October 2024.](#)
- ✓ [MiSCDC Newsletter: December 2024.](#)

CONCLUSIONS

Since the release of the 2015 SCD Strategic Plan, significant headway has been made within each of the seven goal areas, as evidenced throughout the report. But more than being a set of activities to be counted, these activities fit within a public health framework called the Essential Public Health Services (EPHS). The EPHS defines the types of activities necessary for health improvement to be achieved within communities.

The EPHS framework identifies 10 specific categories of public health services:

1. **Assess and monitor population**

health status, factors that influence health, and community needs and assets.

2. **Investigate, diagnose, and address health problems and hazards** affecting the population.

3. **Communicate effectively to inform and educate** people about health, factors that influence it, and how to improve it.

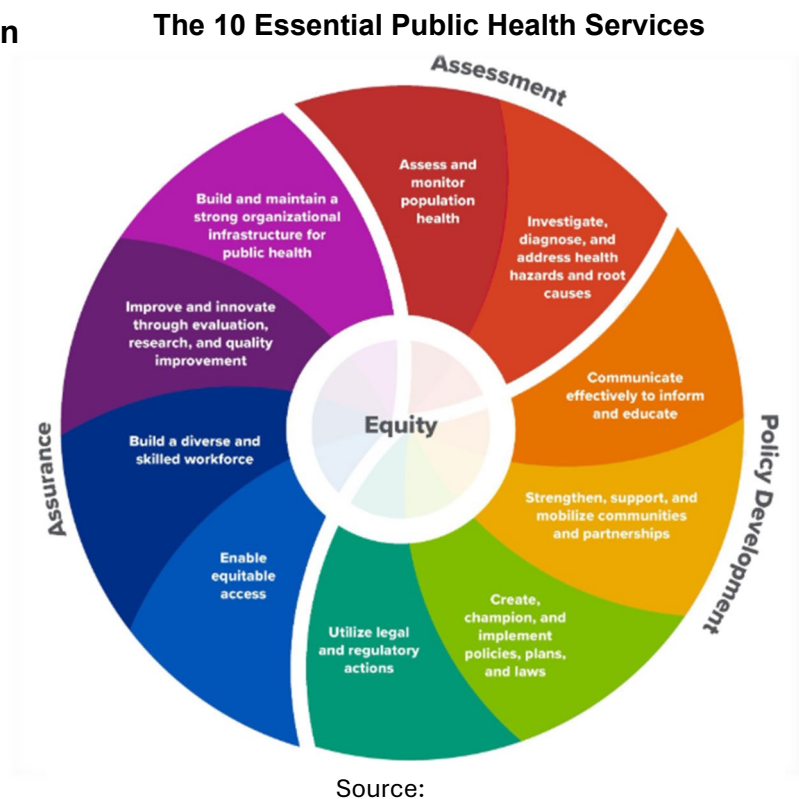
4. **Strengthen, support, and mobilize communities and partnerships** to improve health.

5. **Create, champion, and implement policies, plans and laws** that impact health.

6. **Utilize legal and regulatory actions** designed to improve and protect the public's health.

7. Assure an effective system that **enables equitable access** to individual services and care needed to be healthy.

8. **Build** and support **a diverse and skilled** public health **workforce**.



9. **Improve and innovate** public health functions through ongoing **evaluation, research,** and continuous **quality improvement.**

10. **Build and maintain a strong organizational infrastructure for public health.**

Each activity identified within the individual strategic plan goal areas has been reviewed and assigned to a specific EPHS service area, based on the description of that service. The broad array of essential services implemented has been impactful and has helped create opportunities to achieve optimal health for those with SCD.

Summary: Accomplishments by Goal Area & Ten Essential Public Health Services

	Goal 1: Education/ Awareness	Goal 2: Transition	Goal 3: Provider Shortages	Goal 4: Psycho- social/ MH Supports	Goal 5: Medication Adherence	Goal 6: Day Treatment Clinics	Goal 7: Research	Total
EPHS #1	1	1	1		5		38	46
EPHS #2	2			1				3
EPHS #3	24	5		1			19	49
EPHS #4	23	3	2	3				31
EPHS #5	1	1	7					9
EPHS #6	1							1
EPHS #7		3	7	8	1	4		23
EPHS #8	10	2	4					16
EPHS #9		3	4		1			8
EPHS #10		1						1
Total	62	19	25	13	7	4	57	187

Since 2015, at a minimum, 187 activities have been completed. Some of these activities have been large, multi-year endeavors, such as establishing the Comprehensive Adult Sickle Cell Center at HFH; or enrolling adults with SCD into CSHCS as part of its age eligibility expansion efforts. Others, while smaller (i.e.,

development of handouts, toolkits, webinars, etc.) have addressed a specific identified need. All these efforts have worked in concert to move Michigan forward in addressing systemic and structural barriers to quality health care, while simultaneously responding to urgent needs that mitigate disparities associated with SCD. These efforts strengthen MDHHS as it works to fulfill its mission to provide services and administer programs that improve the health, safety, and prosperity of the residents of Michigan.

Appendix A - Call to Action

SICKLE CELL DISEASE PARTNERS CALL TO ACTION IN MICHIGAN

PUBLIC HEALTH

- ❖ Assess services to document gaps in care and identify opportunities which benefit patients and families.
- ❖ Expand eligibility for Children's Special Health Care Services (CSHCS) to adults ages 21+ with sickle cell disease (SCD) to ensure that all patients have access to adequate health benefits for prevention and treatment.
- ❖ Promote preventative care, health education, and expansion of patient support services.

"Addressing the needs of adult patients has been a challenge for many years, however with the new opportunity to expand CSHCS eligibility for those with SCD over age 21, innovative efforts are being implemented to enhance and improve care quality. As CSHCS begins to look at innovative ways to improve the systems of care for those with medical complexity, addressing the significant challenges faced by individuals with SCD is imperative."

Lonnie Barnett, MPH, CSHCS Division Director - MDHHS

HEALTHCARE

- ❖ Improve health outcomes and patient experience through establishment of primary care and specialty providers knowledgeable in SCD care.
- ❖ Reduce barriers to a successful transition from pediatric to adult care for individuals between ages 14 – 21.
- ❖ Maximize service delivery through expansion of Children's Multidisciplinary Service clinics utilizing health professional teams to offer coordinated, comprehensive, family-centered, and community-based care.

"This is an impactful time in Michigan. Along with our partners and patients we sit at the precipice of creating real change in medical settings for people with sickle cell disease. We have a long way to go to reach health equity where sickle cell is concerned. There's no time like the present to create systematic change."

Dr. Wanda Whitten-Shurney, CEO/Medical Director, SCDAA – MI Chapter

EDUCATION

- ❖ Increase utilization of timely and appropriate preventative care and disease modifying therapies.
- ❖ Support community-based services that provide advocacy, outreach, and resources to patients.
- ❖ Collaborate with stakeholders to develop policies and opportunities to reduce health inequities.
- ❖ Improve treatment adherence by increasing payer and provider educational opportunities about care.

"Although SCD was first recognized over 100 years ago, there is still a lack of knowledge about SCD. A major focus of our efforts is to educate the public, patients, and health professionals."

Dominic Smith, MSA, Public Health Genomics Manager - MDHHS

DATA

- ❖ Partner with the Centers for Disease Control and Prevention to establish a comprehensive national and state data repository to improve incidence and prevalence data, better identify health disparities, evaluate strategies to improve quality of life, and lower healthcare costs.
- ❖ Convene statewide, multidisciplinary partnerships to guide the focus and dissemination of data findings.
- ❖ Develop quality of care measures for Michigan Medicaid Health Plans to incentivize quality improvement.

"The SCD Data Collection Program integrates a wide range of clinical and public health data for persons living with SCD in Michigan. By doing so, the Program will facilitate improvements in the management of SCD across the state."

Dr. Sarah Leasure-Reeves – UofM CHEAR



SUSAN B. MEISTER CHILD HEALTH
EVALUATION AND RESEARCH CENTER
MICHIGAN MEDICINE

Appendix B – Center of Excellence, (June 21, 2023)

HENRY FORD HEALTH

Sickle Cell Clinic Expansion & Enhancement Program Update

Asif Alavi, MD

Co-Director, Adult Sickle Cell Clinic

1

History

- SCD clinic established in 2015
- Staffing initially limited, but utilized resources from HTC
- City-Wide Pain Initiative led by Lara Zador
- Decision to establish adult sickle cell center of excellence with support from HF administration in early 2022
- Asif Alavi joined Henry Ford in November 2022

HENRY FORD HEALTH



2

Sickle Cell Clinic Expansion and Enhancement



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3

3

2022 Objectives



HENRY FORD HEALTH

4

4

2023 Objectives

1

Enhance referral process to our adult sickle cell clinic

2

Improve pain management practices

3

Create a CMDS clinic

4

Explore sharing individual-level, identifiable patient level data with the SCDC

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5

5

Transition Program

- Working with CHM to transition young adult patients to HF SC Clinic
- Quarterly Meeting with CHM
- Coordinated efforts with CHM transition nurse

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6

Pain management

- City-Wide Initiative
- Outpatient pain management guidelines
 - Safer use of opioids
 - Buprenorphine protocols
- Day treatment center
- Integrative therapies

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7

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Subspecialty Care

- Identified Health System partners across a variety of specialties
- Integrated Nephrology clinic began in 2022
 - Scope to be further expanded this year
- Exploring collaboration with Pulmonary Hypertension

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CMDS Clinic

- Patient's being actively enrolled in CSCHS
- Applying for CMDS designation
- Epic build



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SCDC

- Members of HF team attended Annual MiSCDC meeting in March 2023
- Explored sharing individual patient data
- Discussed collaboration on study design/ideas

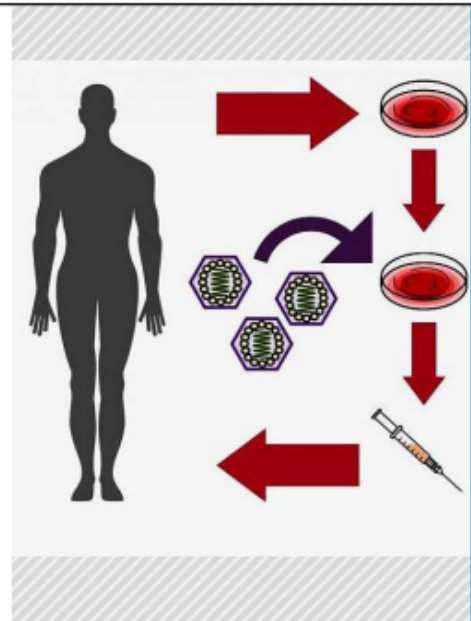


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"Curative" therapies

- Allogeneic Stem Cell Transplant
- Gene therapy
 - Long term followup study
 - New study openings later this year
 - Vertex (Exa-cel)



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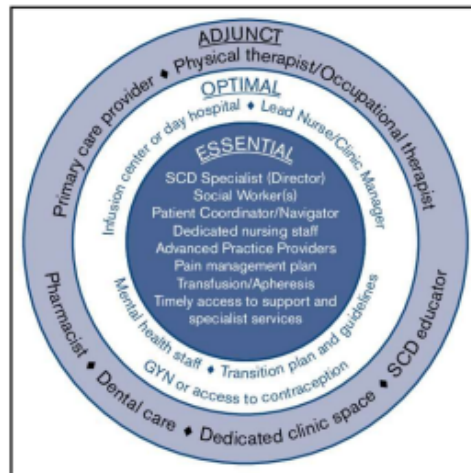
Challenges

- Setting small, but attainable and measurable objectives
- Data, Data, Data!
 - Met with Epic analytics team to discuss acquiring data from epic
 - Plan to hire data manager

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Kanter, et al. Blood Advances 2020

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5-year plan

- Streamlined transition program
- Optimization of management of both acute and chronic pain
- Subspecialty collaboration to address organ complications of SCD
- Fully operational CMDS clinic
- Apheresis
- Robust "curative" therapies program
- Data collection
- Research Program
- Collaborations with other SCC
- Medical Home with primary care
- Mental Health Services
- Support Services: Dietitian, Social Work, Community Health, Physical therapy

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Summary (i.e. how did SCCEE help us?)

- SCCEE funding provided valuable funding to allow for a multidisciplinary team to act on priorities for development of Comprehensive Sickle Cell Clinic.
- This "seed" fund will allow us to grow into a Comprehensive sickle cell clinic to serve the adult population of Metro Detroit and the state of Michigan

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Alex Glaros
Melony Avella-Howell

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Special Thanks



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Appendix C – Summary Table of Goals, Strategies and Tactics

Goal I: EDUCATION & AWARENESS —To develop statewide multi-level messaging and communication strategies to increase awareness of SCD, disease-modifying medical therapies, and SCT.

STRATEGY 1: Increase activities with public and private organizations to raise awareness among targeted segments of the general and patient population about SCD/SCT and its implications.

Tactic		Not Initiated	Ongoing	Complete
1.a.	Develop a multi-level education strategy to inform the public at-large about the burden of SCD; reach those who have, or are at risk of having SCT, and educate individuals with SCD to increase use of disease-modifying therapies.		✓	
1.b.	Work with SCDA-MI and UM to develop targeted health education materials that include general SCD information, issues related to stigmatization, transition of care, pain management, genetic counseling, hydroxyurea, and the Family Medical Leave Act (FMLA).		✓	
2.a.	Work with SCDA-MI, Maternal Child Health (MCH) programs, CSHCS, and the Family Center to connect services for individuals and families with special health care needs.		✓	

Tactic		Not Initiated	Ongoing	Complete
2.b.	Distribute information to providers on lifecourse approaches to care transitions specifically related to SCD.		✓	
2.c.	Include SCD information in Health Plan provider notices.	✓		
2.d.	Explore the potential to collaborate with the DMC and CHM to establish a one-year sickle cell fellowship program to exclusively train physicians, physician assistants, and nurses.			✓
3.a.	Explore interest in developing a statewide SCD coalition; seek involvement from Michigan Health & Hospital Association, Michigan Primary Care Association, Legislative Black Caucus, school-based health centers, LHDs, health care providers, community-based organizations (CBOs), and consumers.		✓	
3.b.	Promote public participation in rallies and walks to increase awareness.		✓	
3.c.	Provide in-service training opportunities for MDHHS programs.	✓		

STRATEGY 2: Increase capacity within MDHHS programs to incorporate SCD into public health programming.

Tactic		Not Initiated	Ongoing	Complete
4.a.	Partner with MDHHS programs to deliver SCD and SCT education to their respective target populations (i.e., providers, pregnant women, young children, and teenagers).		✓	
4.b.	Post health education materials on the MDHHS website.			✓
5.a.	Explore opportunities to utilize the Home Visiting Network and Text for Baby to send medication (i.e., penicillin, hydroxyurea) and immunization reminders and/or notification alerts.	✓		
5.b.	Review assessment and screening tools to incorporate applicable SCD questions to identify individuals with the condition and provide information and resources to reduce barriers.			✓
5.c.	Conduct outreach and provide informational materials to schools, colleges, and community-based programs (i.e., Federally Qualified Health Centers [FQHCs], CAHCs to increase awareness of SCD.	✓		

Tactic		Not Initiated	Ongoing	Complete
6.a.	Distribute and update special immunization recommendations to providers; add SCD-specific materials to the Alliance for Immunization in Michigan (AIM) - Adolescent Immunization Toolkit and distribute to LHDs, Vaccine for Children (VFC) providers, and high-risk clinics.			✓
6.b.	Develop immunization rates - specific to SCD to monitor long-term trends.			✓
6.c.	Assess Michigan Care Improvement Registry (MCIR) and Health Level 7 (HL7) messaging capacity to develop SCD notification module for providers.			✓
7.a.	Provide in-service training on SCD via Grand Rounds once every 2 years for CAHC staff, and annually for school nurses/school staff.		✓	
7.b.	Develop SCD education packet on family planning decisions for use in CAHC centers.	✓		
8.a.	Develop a resource registry of SCD resources for CSHCS Family Center.		✓	

Tactic		Not Initiated	Ongoing	Complete
8.b.	Increase awareness and utilization of the Family Center's parent mentor matching program for SCD clients.		✓	
8.c.	Increase awareness and utilization of the county-level Parent to Parent Support among families living with SCD.		✓	
8.d.	Recruit parents of children with SCD to participate in mentor training to become mentors to other parents.		✓	

Goal II: TRANSITION —To develop and implement strategies for improving the transition from pediatric to adult care.

STRATEGY: Increase resources and tools for specialty clinics, community-based organizations/clinics, and health care providers to utilize in order to systematically enhance the transition process for patients.

Tactic		Not Initiated	In Progress	Complete
1.a.	Identify the role of CMDS in supporting clinic teams to address transition, including mechanisms for enhanced medical care using a team approach that includes a physician and a nurse/physician assistant at a minimum and if possible, a social worker and/or case manager.			✓
1.b.	Identify strategies and systems to aid specialty clinics in promoting transition from pediatric to adult care.			✓

Tactic		Not Initiated	In Progress	Complete
1.c.	Identify approaches to reducing barriers surrounding establishment and utilization of transition care programs (i.e., creative financing solutions).		✓	
2.a.	Identify and promote best practices for client, parent, and caregiver education to achieve competence in areas of independence and medical systems navigation.		✓	
2.b.	Disseminate information to groups or forums where patients with SCD can share ideas and support one another.		✓	
3.a.	Build patients' knowledge and skills to understand and manage their health, health care needs, and to advocate for themselves.		✓	
3.b.	Prepare parents to support patients' independence.		✓	
3.c.	Provide patient resources for ongoing health needs (i.e., reproductive health, genetic counseling, oral health, sickle cell complications that increase with age, maternal health needs).		✓	
4.a.	Explore interest in developing a working group designated for nurses, case managers, health educators and		✓	

Tactic		Not Initiated	In Progress	Complete
	social workers to address transition tactics.			
4.b.	Identify strategies to facilitate communication among patients, families, and providers.		✓	
5.a.	Develop a transition checklist for specialty clinics and primary care providers that includes pain management education and planning, peer mentoring, immunization education, trait education, genetic counseling, and resource awareness.			✓
5.b.	Create a targeted transition education initiative in CAHC program.		✓	
6.a.	Initiate a pilot project to identify primary care providers in Detroit area with the highest number of adolescent patients with SCD and partner to identify unmet needs.	✓		
6.b.	Work with CAHC program providers to address the needs of students with SCD. Conduct key informant interviews. Create transition education materials.		✓	

Goal III: PROVIDER SHORTAGE —To increase availability of providers who treat all aspects of SCD with an emphasis on increasing providers for adults.

STRATEGY: Increase the number of providers caring for sickle cell patients in Michigan.

	Tactic	Not Initiated	In Progress	Complete
1.a.	Investigate medical school scholarship opportunities and loan repayment policies for physicians to practice in underserved areas (i.e., primary care physicians for children, hematologists for adults).	✓		
2.a.	Explore existing educational tools and identify training gaps; explore sources to increase specialty education and training opportunities for providers.	✓		
2.b.	In collaboration with the Midwest region HRSA grant initiative, organize education and training opportunities for health care providers treating patients with SCD.		✓	
2.c.	Share NHLBI Evidence-Based Management of SCD Guidelines with the primary care provider of every baby diagnosed with SCD.	✓		
2.d.	Collaborate with HemQIC and Michigan Quality Improvement Consortium to identify activities, training opportunities, and incentives that will be needed to increase the	✓		

Tactic		Not Initiated	In Progress	Complete
	number of providers treating patients with SCD.			
2.e.	Identify and apply for applicable funding opportunities.		✓	
3.a.	Quantify the ratio of pediatric and adult hematologists in relation to target population residential location to demonstrate the need to increase provider capacity.	✓		
3.b.	Assess enrolled CSHCS subspecialty providers caring for children and youth with SCD to determine gaps in provider mix compared to other disorders.	✓		
3.c.	Identify opportunities to foster specialist and primary care provider joint case management through use of telemedicine.		✓	
4.a.	Review MHP Guidelines and compare them to NHLBI Evidence Based Management of SCD Guidelines. Develop Michigan specific guidelines that reflect national standards.		✓	
5.a.	Develop a SCD pain training module for nurses and provide continuing education credits (CEUs).			✓

Goal IV: PSYCHOSOCIAL / MENTAL HEALTH SUPPORT —To increase recognition of the need to address psychological issues and provide mental health support for individuals living with SCD and their families.

STRATEGY: Increase partnerships and resources for mental and behavioral health providers to decrease rates of psychiatric morbidity in the SCD population.

Tactic		Not Initiated	In Progress	Complete
1.a.	Identify relevant programs and points of contact within MDHHS to address psychological and mental health needs.		✓	
1.b.	Identify existing psychological needs assessment tools suitable for patients and families affected by SCD.		✓	
1.c.	Identify relevant programs to support reproductive counseling and prenatal education.		✓	
1.d.	Promote access to substance abuse treatment services for individuals with SCD as needed.		✓	
2.a.	Promote alternative and/or holistic therapies for acute pain management.		✓	
3.a.	Promote alternative and/or holistic therapies for acute pain management.		✓	
3.b.	Partner with the MDHHS Community Services Bureau to improve awareness and identify community resources that will provide assistance to	✓		

Tactic		Not Initiated	In Progress	Complete
	individuals living with SCD.			
4.a.	Share guidelines for treating emergency room patients who are both in pain and drug-seeking.		✓	
4.b.	Identify partnerships to develop training for emergency room staff to treat patients who are in pain and potentially drug-seeking.		✓	

Goal V: MEDICATION ADHERENCE — To develop protocols for improving medication adherence in accordance with the NHLBI Evidenced-Based Management of SCD Guidelines.

STRATEGY: Increase understanding of patient motivating factors for medication adherence.

Tactic		Not Initiated	In Progress	Complete
1.a.	Characterize barriers to patient adherence for recommended treatments.		✓	
1.b.	Collaborate with partners to identify and promote initiatives to overcome barriers and improve self-managed adherence.		✓	
1.c.	Support education to promote the adoption of model treatment practices and disease modifying therapies.		✓	
1.d.	Assess the effectiveness of task-focused communication technology (i.e., Glocap, VOICE Crisis	✓		

Tactic		Not Initiated	In Progress	Complete
	Alert) in improving adherence.			
2.a.	Promote uniform practice guidelines among specialty providers; Use an established prescribing and monitoring protocol.	✓		
3.a.	Conduct literature review to identify myths and strategies to dispel myths and promote facts about SCD patient attitudes, behaviors, and cultural competence.		✓	
3.b.	Identify and disseminate written patient materials with plain language information.		✓	

Goal VI: DAY TREATMENT CLINICS — To improve acute care in the emergency room or alternative settings.

STRATEGY: Partner with hospital systems to promote opportunities, training, and best practices to increase patient satisfaction in the emergency room or alternative settings.

Tactic		Not Initiated	In Progress	Complete
1.a.	Identify best practices for acute pain management in various health care settings.		✓	
1.b.	Identify strategies for the successful dissemination and implementation of best practices in collaboration with partners.		✓	
1.c.	Compile and distribute best practice recommendations and		✓	

Tactic		Not Initiated	In Progress	Complete
	algorithms that can be adapted for use in various acute settings.			
2.a.	Promote continuous quality improvement projects to reduce ED wait time to initial administration of pain medication.	✓		
3.a.	Assess the feasibility and cost-benefits of establishing additional day treatment clinics.			✓
3.b.	Investigate public and private funding sources to support day treatment programs (i.e., DMC, Hurley Hospital).		✓	

Goal VII: RESEARCH — To establish a Michigan SCD Consortium to coordinate public health research efforts within the state of Michigan.

STRATEGY: Increase public health capacity to facilitate research opportunities in Michigan.

Tactic		Not Initiated	In Progress	Complete
1.a.	Develop a consortium to coordinate public health research efforts; establish panel experts in SCD, appropriate specialists — emergency medicine, pain medicine, psychology, primary care providers, patients, public health, hematology.		✓	
1.b.	Facilitate periodic community partner meetings and symposia to share progress on the MDHHS SCD strategic plan, management		✓	

Tactic		Not Initiated	In Progress	Complete
	updates, research priorities and quality assurance outcome measures for discussion and consensus development.			
1.c.	Review core hemoglobinopathy indicators annually.		✓	
1.d.	Update and distribute SCD data on a regular basis.		✓	
2.a.	Identify and promote implementation of a SCD research agenda for public health.		✓	
2.b.	Review available qualitative and quantitative data relating to SCD management.		✓	
2.c.	Promote public health research initiatives to improve health outcomes for individuals with SCD.		✓	

Appendix D – State and Federal Funding Sources

- ✓ State of Michigan Newborn Screening State Restricted Fees.
- ✓ State of Michigan General Funds.
- ✓ U.S. Department of Health and Human Services – Center for Medicare and Medicaid Services, Medical Assistance Program (93.778) FY 2022 - 2025.
- ✓ U.S. Department of Health and Human Services- Health Resources and Services Administration: HRSA-14-078.
- ✓ U.S. Centers for Disease Control and Prevention: CDC-RFA-DD-19-1906.
- ✓ U.S. Centers for Disease Control and Prevention: CDC-RFA-DD-23-0002 (Recipient of two University of Michigan sub-awards).

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