**Section 663.200 Sickle Cell Statewide Impact and Surveillance Program**

The Department will develop and establish the Illinois Sickle Cell Impact Surveillance System (ISCISS) to assess and monitor the impact of sickling disorders on Illinois residents. ISCISS activities will include assessing the impact and unmet needs related to sickling disorders, as well as additional hemoglobinopathies which may impact the health and wellbeing of affected persons.

a) Through ISCISS, *IDPH shall perform a study of the prevalence, impact, and needs of individuals with sickle cell disease and sickle cell trait in Illinois. On a biennial basis, the study* shall *include*, but not be limited to, *all of the following* (Section 131-25 of the Act):

1) *The prevalence, by geographic location,* of people *diagnosed with sickle cell disease in Illinois.*

2) *The prevalence, by geographic location,* of people with sickle cell trait *in Illinois;*

A) *The availability and affordability of screening services* for sickle cell trait in Illinois;

B) *The location and capacity for the treatment of sickle cell disease and sickle cell trait* including:

i) *Treatment centers;*

ii) *Clinics;*

iii) *Community-based social service organizations; and*

iv) *Medical specialists.*

C) *The unmet medical, psychological, and social needs* of people *in Illinois with sickle cell disease;*

D) *The underserved areas of Illinois for the treatment of sickle cell disease, and*

E) *Recommendations for actions to address any shortcomings in the State identified under this Section.*

F) The prevalence, impact, and unmet needs of people with additional sickling disorders and additional hemoglobinopathies which may impact the health and wellbeing of people in Illinois.

3) In establishing the ISCISS, and developing, implementing, and conducting program activities, the Department will collaborate with multiple partners and stakeholders, including, but not limited to (Section 131-25 of the Act):

A) *The Center for Minority Health Services*;

B) *Health care providers that treat people with sickle cell disease*;

C) People *with sickle cell disease*;

D) *Representatives of community-based organizations that serve* people *with sickle cell disease*; and

E) The DPH Newborn Screening Program.

4) The Department shall develop a report of its findings before July 1, 2024, and biennially thereafter. The Department shall submit the report to the General Assembly.