

## PROGRAM WORK STATEMENT

FY 2017 Social Service Contract funded by Travis County

Date prepared: 05/31/2016

### Instructions:

- Answer the following questions as they pertain to *only those programs and services in which Travis County invests*.
- Ensure that all language (e.g. agency and program names, performance measures, etc.) is consistent across all contract forms.
- Do not delete any instructions or question descriptions.
- The information contained in this document will be used to report on your program to the Travis County Commissioners Court and the public, so the information herein should accurately explain and reflect the program and services.

### 1. Program Information

*Provide agency name and program name as they appear on all contract documents.*

Agency: Austin/Travis County Health and Human Services Department

Subcontractor: Sickie Cell Anemia Association of Austin

Program names: Sickie Cell and Health Equity- SC programs

### 2. Program Goals

*Briefly describe the goals of the services purchased by Travis County in this contract.*

There are 2 million Americans that carry the “silent” sickle cell trait. It is often called silent because most individuals are not aware that they carry the trait. Populations impacted are primarily African Americans, Hispanics/Latinos, Asians, Italians, Greeks and people of Mediterranean descent as well as Caucasians. Sickie Cell Disease is a genetic blood disorder that attacks the red blood cells. It causes chronic pain, jaundice, strokes, organ damage, and other debilitating and life-threatening conditions. Life expectancy for this chronic condition is approximately 40 years of age and there is no cure.

The severity of this debilitating disease has been recognized by the state of Texas. The Texas Department of State Health Services screens for a total of 29 disorders including cystic fibrosis, Phenylketonuria (PKU), Congenital Hypothyroidism and Galactosemia (GAL) in newborns along with sickle cell hemoglobinopathies. Out of the 29 disorders tested, sickle cell disease is the most common disorder and it outnumbers all others by 5 to 1. Due to the magnitude of this severe public health condition, the Texas Department of State Health Services Newborn Screening Unit conducts mandatory newborn screening testing for sickle cell trait.

Sickle Cell Anemia Association of Austin is the only referral organization to provide resources, peer navigation assistance and education to populations affected by sickle cell disease in the Austin/Travis county region. Additionally, we are the only organization that serves this underserved population in Austin/Travis County and we are the only organization that local hospitals, the Texas 2-1-1 Referral line and the Department of State Health Services refer parents and individuals to regarding this condition.

Sickle Cell Anemia Association of Austin staff acts as navigators to help individuals, caregivers, and family members to gain access to resources, respite, newborn sickle cell trait notification, and other support. By educating those affected along with at risk populations our program provides resources that are essential to public health.

### **3. Target Population**

*Briefly describe the target population of this program.*

The Sickle Cell Anemia Association of Austin program is targeted to the City of Austin/Travis County parents of newborns, children, adults and individuals with sickle cell disease, those that carry sickle cell trait, or those who may carry the silent trait. The program further raises awareness, increases knowledge, encourages early detection, prevention, educates about informed decision making and reproductive choices and treatment in this population.

According to the Department of State Health Services, in 2011 and 2012 there were 9,258 babies born with sickle cell trait in Central Texas (Region 7/8). In terms of ethnicity, African Americans were the most impacted, followed by Hispanics and Whites and then Others. In addition, one in twelve African Americans carry the silent sickle cell trait and one in 36 Hispanics/Latinos in Travis County as per the City of Austin Chief Epidemiologist. According to the 2010 Census there were 87,308 African-Americans and 342,766 Hispanic/Latinos. That amounts to 7,275 African-American and 9,521 Hispanic/Latino potential sickle cell patients in Travis County.

#### 4. Client Eligibility

List all eligibility requirements for clients to receive services in the program, and fully describe the criteria for each requirement (see Sample Table below for examples). If eligibility requirements vary by program component, please specify in the descriptions. If your contracted program includes multiple service components with varying eligibility criteria, you may copy/paste the table below, complete one table per component, and title each table accordingly.

Sample Table:

Eligibility Requirement	Description of Criteria	Verification Method
Income level	At least one-half of clients must be at or below 100% FPIG. Remainder can be up to 200% FPIG.	Income level is self-declared based on HUD 24Code of Federal Regulations, part 5.
Residency	Clients must be residents of the five county area: Travis, Williamson, Hayes, Bastrop, Caldwell.	Residency verified by utility bill, lease or rental agreement, or government-issued photo identification.

#### Program Component (if applicable):

Eligibility Requirement	Description of Criteria	Verification Method
Sickle Cell Trait or Disease	The Sickle Cell Program is targeted to City of Austin/Travis County parents, children, adults and individuals with sickle cell disease, those that carry sickle cell trait, or those who may carry the silent trait. All individuals with sickle cell disease or sickle cell trait regardless of income, race, ethnicity, sexual orientation, or religious affiliation are eligible to receive our program services in the City of Austin/Travis County.	Information will be obtained through newborn screening notifications, referrals, sign in sheets, and intake forms. When a client receives navigation services, that information is placed in their file and noted in the quarterly reported system along with the other detailed and pertinent information reported to the City of Austin and Travis County.
Residency	Clients must be residents of the City of Austin or Travis County	Verification of residency will be verified using GIS map verification.

(If program has additional eligibility requirements, insert additional rows in table. Please delete empty rows.)

#### 5. Service Delivery

Describe the services and how they are provided through the program. This should be a clear and concise summary of how clients move from initial contact through exit and follow-up. Include all relevant components of the core services, such as:

- **Outreach:** The Sickle Cell Association provides outreach by going into the community and raising awareness and advocacy for families, individuals with sickle cell disease or sickle cell trait and the community at-large.
- **Intake:** When the Sickle Cell Association receives a new client and gathers information about his/her residency, sickle cell status, if known, and provides other resources that are needed.
- **Eligibility determination process:** All individuals with sickle cell disease or sickle cell trait regardless of income, race, ethnicity, sexual orientation, or religious affiliation are eligible to receive our program services in the City of Austin/Travis County. Our agreement with the Texas Department of State Health Services provides services for the individuals with a medical diagnosis of sickle cell trait and a residence in the state of Texas.

- **Service provision:** The Sickle Cell Anemia Association of Austin program is targeted to the City of Austin/Travis County parents of newborns, children, adults and individuals with sickle cell disease, those that carry sickle cell trait, or those who may carry the silent trait.
- **Duration of service:** Services are provided to unduplicated clients for one year.
- **Termination or discharge:** Clients are terminated and files are marked “inactive” if after multiple contacts a client cannot be reached and/or a client has been unwilling to receive or positively engage in services.
- **Coordination with and referral to/from other agencies:** The Sickle Cell Anemia Association of Austin coordinates its services with Seton Family of Hospitals, Texas Oncology, Dell Children’s Medical Center of Central Texas, Department of State Health Services, 211 Texas Referral line and other community groups to ensure a continuum of care for those suffering from sickle cell disease or sickle cell trait.
- **If applicable, brief description of research or promising practice on which program is based:** The Sickle Cell Association continuously draws upon research-based practices to ensure that the Sickle Cell Association program is providing the most effective services for clients and the community.

Clients referred to the Sickle Cell Anemia Association of Austin receive assistance through the numerous program services. The agency provides services in two categories:

- 1) Notification, Hemoglobinopathy Education and Navigation Services; and
- 2) Community based education.

The Sickle Cell Anemia Association of Austin services are client-centered, community based and are approached on an individual basis with a community emphasis:

1. Notification, Hemoglobinopathy Education and Navigation Services:
  - i. Intake and Navigation Services- The Sickle Cell Anemia Association of Austin receives a new client and gathers information about his/her residency, sickle cell status, if known, and provides other resources that are needed. The clients will often need doctor recommendations and hospital or clinic referrals for treatment. The Sickle Cell Anemia Association of Austin also coordinates with the Texas 211 Referral Line for additional client services. After an initial intake the agency follows the clients through their disease or trait management. The agency’s trained staff acts as a navigator for assistance, care-calls, and provides assistance to hospitalized clients.
  - ii. Financial Assistance: The Sickle Cell Anemia Association of Austin provides limited financial assistance to clients in financial need with their prescription medications, life-situation hardships, and bereavement.
  - iii. Support Group Meetings: The Sickle Cell Anemia Association of Austin provides monthly support group meetings for adults and children with sickle cell disease and/or sickle cell trait to provide unity and companionship while they are battling this disease. This therapeutic forum allows clients to express their concerns, gather support and work collaboratively at further benefiting the affected population.
  - iv. Liaison for clients and their medical doctors: The Sickle Cell Anemia Association of Austin provides assistance and advocacy for clients and families who need assistance in speaking with medical doctors or nurses. At times clients cannot verbally express their concerns to medical doctors and nurses, and the agency provides support to them during their hospital stay or medical visits.
  - v. Newborn screening notification and education: The Sickle Cell Anemia Association of Austin provides notification to the new parents that their newborn has tested positive for sickle cell trait. The agency provides education to the parents who have

received this notice and explains, describes and provides details about sickle cell trait and hemoglobinopathy. As certified Hemoglobinopathy educators, the agency's staff explains the effects of sickle cell trait on the newborns. The staff further educates parents on the need to know their sickle cell status if unknown or if known they are further educated about their status.

- vi. Sickle Cell Camp opportunities: The Sickle Cell Anemia Association of Austin provides sickle cell summer camp opportunities for children affected by sickle cell disease. This provides an educational and therapeutic environment for children with this condition while providing caregivers respite care.
- vii. Certified Hemoglobinopathy Education: The Sickle Cell Anemia Association of Austin educates parents, individuals, groups, and families about sickle cell disease and sickle cell trait in regards to symptoms, treatment and management in English and Spanish. The agency educates parents, groups and individuals about the genetics of the disease and preventative measures.

## 2. Community Based Education:

- i. Health Education about Sickle Cell Disease and Sickle Cell Trait: The Sickle Cell Anemia Association of Austin facilitates health fairs and health presentations to community organizations including but not limited to: churches, schools, state departments, businesses, volunteers, medical professionals, social workers, individuals with sickle cell disease or trait, and the at-risk population who are unaware of their status. The agency addresses different groups and individuals, by facilitating and participating in a comprehensive forum to gain better understanding, best practice and knowledge about sickle cell disease and sickle cell trait in the City of Austin/Travis County area while targeting at risk populations. The agency provides expertise in giving presentations and working with a number of community based organizations.
- ii. Outreach, awareness, and advocacy: The Sickle Cell Anemia Association of Austin provides outreach by going into the community and raising awareness and advocacy for families and individuals with sickle cell disease or sickle cell trait. The agency works on dispelling misconceptions, stereotypes, and further addressing the needs of this at-risk and underserved population.

All the listed services are provided in collaboration with other agencies in Travis County (please see the section below).

The Sickle Cell Anemia Association of Austin collaborates and coordinates its services with Seton Family of Hospitals, Texas Oncology, and Dell Children's Medical Center of Central Texas to ensure a continuum of care for those suffering from sickle cell disease. Clients are referred to the agency for resources, education and support by these entities. The agency in return recommends clients to these healthcare providers when necessary. In addition, the Sickle Cell Anemia Association of Austin partners with the above listed entities for a medical conference.

The Sickle Cell Anemia Association of Austin collaborates with the Department of State Health Services Newborn Screening Department. The Department of State Health Services Newborn Screening Department screens and tests newborn babies for sickle cell disease and sickle cell trait. The agency partners with this department in navigating the notification system for parents of newborns in Central Texas, region 7/8, and beyond. After notification has been sent to the parents of newborns the agency further educates these parents about this disorder along with future ramifications.

The Sickle Cell Anemia Association of Austin partners with many other community organizations that provide their services in Travis County, including but not limited to: the African American

Quality of Life Initiative, African American Alliance, Austin Area African American Behavioral Health Network, Huston Tillotson University, March of Dimes, Texas Education Agency, Texas Department of Insurance, University of Texas at Austin, Univision, Nineteenth Street Baptist Church, Greater Mount Zion Church, Pleasant Grove Baptist Church, Greater Union Baptist Church, and Saint Mary's Baptist Church.

Through the partnership with these organizations, the Sickle Cell Anemia Association of Austin secures presentation opportunities in front of various congregations, attends and participates in educational meetings that affect the Austin/Travis County population, navigates community health education, and collaborates and partners with community events and other services provided in Travis County.

## 6. Service Accessibility

Describe any relevant strategies employed by the program to ensure service access related to the following issues:

- Cultural competence: The Sickle Cell Association provides services in a culturally sensitive and inclusive manner.
- Language and communication access: The Sickle Cell Association has bilingual staff and volunteers, to assist with Spanish, Mandarin and Hindi speaking LEP Hispanic and Asian American clients.
- Geographical access: Services are provided to clients located in the City of Austin and/or Travis County.
- Anti-discrimination strategies: All individuals with sickle cell disease or sickle cell trait regardless of income, race, ethnicity, sexual orientation, or religious affiliation are eligible to receive Sickle Cell Association program services in the City of Austin and Travis County.
- Other accessibility issues relevant to the program: The Sickle Cell Association continues to strive to provide the most up to date and most effective services for clients.

## 7. Program Staffing

*List the staff positions (titles only, no individual names) that are essential to this program, and provide a brief description of duties as they relate to this program. If there are multiple staff positions with the same title and duties, you can note the number of positions with the position title, e.g. "Case Manager (5)."*

Position Title	Description of Duties
President	Oversees programming, staff, leadership and direction for the program
Chief Operating Officer	Maintains programming productivity, manage client services and maintain contract compliance
Client Services Specialist (2)	Provide education, outreach, and navigation services
Administrative Assistant (2)	Provide education, intake, screen calls, maintain files and other needs.

*(If program has additional staff positions, insert additional rows in table. Please delete empty rows.)*

## 8. Program Evaluation

### a) Information Management and Data Collection

- Describe the **tools and processes** used to collect program data, and the **systems** used to manage program data (i.e. client data, service information, or other data relevant to the program's overall service delivery and performance).
- If any surveys are used to collect information used in performance reporting, please provide a description of survey procedures (such as when, how, and by/to whom the survey is distributed, received, completed, and returned) and a copy of the most recent survey as an addendum.

Program data will be collected, analyzed, and reported to the City. Newborn screening notifications will be collected and analyzed making sure clients are in Austin/Travis County by verification of residency, reflecting either Austin Full Purpose, or Travis County. Documented evidence will be placed in the Newborn screening binder from the Department of State Health Services with documented proof of residency in Travis County and/or the City of Austin.

b) Performance Evaluation

*Describe how the agency uses the data it collects to evaluate both programmatic effectiveness (as described in questions 2 and 5 of this work statement) and progress towards performance goals (as described in 9 and 10 of this work statement).*

The Sickle Cell Anemia Association of Austin conducts monthly care calls for continuous feedback from the clients. The agency also provides an optional survey to collect feedback from the clients. The survey is available to clients during initial and follow-up meetings.

c) Quality Improvement

*Describe how the agency uses its evaluation results to: identify problems or areas for improvement in service delivery; design strategies to address these problems; implement those strategies; and follow up to ensure corrective actions have been effective.*

The Sickle Cell Anemia Association of Austin Board reviews financial reports and receives progress updates about the agency. The Board is constantly evaluating and seeking opportunities for expanding the agency's services. Quarterly reports are sent to the Contract Manager for data review and performance monitoring.

The agency utilizes various ways of conducting quality improvement activities. For instance, the first annual Sickle Cell Anemia Association of Austin Board Meeting is conducted to establish the agency's annual strategic plan. The agency reviews the process issues with the Board and ensures that the annual strategic plan is followed. In addition, the operational issues are handled through the management chain-of-command and during staff meetings. Finally, the satisfaction surveys are offered to clients and reviewed to further implement improvements and quality control.

**9. Output Performance Measures**

*Enter the output performance measures to be reported for the program in quarterly performance reports. You must report the number of unduplicated clients served and at least one other output. Total annual goals should be 12-month goals. Outputs should be reported quarterly unless a specific programmatic or data-driven limitation exists. Please use the comments section to specify and provide explanation for any reporting exceptions.*

Output Measure	Total Annual Goal	Quarters Reported
1. Total number of unduplicated clients provided with Community-Based Education	2,260	1,2,3,4
2. Number of unduplicated clients with sickle cell trait or disease provided with notification and hemoglobinopathy education	123	1,2,3,4

*(If approved for additional Output measures, insert additional rows in table. Please delete empty rows.)*

**Comments** (for reporting exceptions, if applicable):

**10. Outcome Performance Measures**

*Enter the outcome performance measures (numerators, denominators, and outcome rates) to be reported for the program in quarterly performance reports. Total annual goals should be 12-month goals. Outcomes should be reported quarterly unless a specific programmatic or data-driven limitation exists. Please use the comments section to specify and provide explanation for any reporting exceptions.*

Outcome Measure	Total Annual	Quarters Reported
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			Goal	
1.	a.	Total number of unduplicated clients with sickle cell disease or sickle cell trait provided with navigation services (numerator)	107	1,2,3,4
	b.	Number of unduplicated clients with sickle cell trait or disease provided with notification and hemoglobinopathy education (denominator)	123	
	c.	Percent of unduplicated clients with sickle cell disease or sickle cell trait provided with navigation services (rate)	87%	

*(If approved for additional outcome measures, insert additional rows in table. Please delete empty rows.)*

**Comments** (for reporting exceptions, if applicable):

## 11. Community Planning

### a) Community Planning Group Participation

*If the agency participates in any community planning groups relevant to the issue area and services under this contract, please list them here, along with the name and title of agency representatives who participate and a brief description of their role and participation in that planning group.*

Community Planning Group	Agency Participant Name/Title	Participation Role/Description
One Voice Central Texas	Alysian Thomas/Chief Operations Office & Staff Attorney (primary) Linda Wade/President (secondary)	Agency Member

*(If agency is involved in additional planning groups, insert additional rows in table. Please delete empty rows.)*

### b) Community Plan

*If the agency aligns itself with a Community Plan, provide the name of the plan and its authoring body, and a brief description of how you align your agency with and respond to the plan's shared community goals. If there is not an established community plan in this issue area, describe what the agency uses to orient itself to community needs and goals.*

The Sickle Cell Association takes an active role in planning and organizing with the community to ensure services. The Sickle Cell Association participates in several community events to promote education and awareness which will reduce health disparities. The Sickle Cell Association is also a member of One Voice, and also serves on its Public Policy Board to ensure community efforts are heard. The Sickle Cell Association is also the only sickle cell agency in Central Texas that is recognized by the National Sickle Cell Disease Association of America.

### c) Response to Community Change

*Have there been, or do you anticipate, any changes to the community plan or community goals, that will impact how you provide services over the remainder of your contract period?*

The Sickle Cell Association does not anticipate any changes.