Goal 2

Summary

Through participation of the Oklahoma Genetics Advisory Council (OGAC) and its committees a comprehensive representative action plan for goal 2 was developed. The *State Genetics Plan's* three objectives for goal 2 include: (1) public health genetic infrastructure development, (2) system linkages to better serve children with special health care needs (CSHCN) population, and (3) clinical genetic services. The combined Public Health Policy and Evaluation Committee of OGAC identified five action steps as priority for implementation.

Goal 2 Action Plan

"Develop and maintain a responsive public health genetics program to plan, implement, monitor, and evaluate genetics education and services in Oklahoma."

Objective 1- The OSDH will develop and sustain a responsive, collaborative, culturally sensitive, and effective public health genetics program that links with community partners and addresses health disparities.

Action Steps (◇ symbol identifies prioritized action steps):

- ◇ Identify stable funding sources for the public health genetics program (priority number 2).
- ◇ In collaboration with Oklahoma Genetics Advisory Council (OGAC), establish a network to address and monitor local ethical, legal, and social issues related to genetics including confidentiality and discrimination, e.g., life insurance discrimination based on genetic testing, inflated insurance premiums due to a diagnosis of a genetic disorder, or Medicaid eligibility (priority number 3).
- ○ Establish a system for the public to report incidents of insurance and employee discrimination related to genetics.
- ○ Maintain a full-time State Genetics Coordinator at the OSDH to provide oversight of the implementation of the *State Genetics Plan* and to administer the public health genetics program.

- ○ Maintain the genetics advisory council (Oklahoma Genetics Advisory Council) as a diverse and active advisory group involved in strategic planning and evaluation of genetic programs.
- ○ Provide annual presentations on cultural diversity to OGAC.
- ○ Collaborate with the Family Advisory Committee of OGAC to ensure genetics services and information are culturally sensitive.
- ○ Establish a system to monitor and evaluate program performance.
- ○ Addition of members representing minority cultures to OGAC and its committees, i.e., Native American, African Americans, Hispanic, and Asian.
- ○ Through education and collaboration with community partners, provide public health leadership to promote quality genetics services in Oklahoma that are accessible and culturally sensitive.
- ○ In collaboration with the Public Health Policy Committee of OGAC, develop strategies to improve reimbursement for genetic services.
- ○ In collaboration with the Public Health Policy Committee of OGAC, determine an appropriate organizational structure for a public health genetics program within OSDH, including potential staffing and financial needs.
- ○ Network with national organizations to assist with program development for quality genetic services in Oklahoma, i.e., Genetic Alliance, Coalition of State Genetics Coordinators, International Society of Nurses in Genetics, National Newborn Screening and Genetics Resource Center, CDC Office of Genetics and Disease Prevention, American Society of Human Genetics, National Society of Genetic Counselors, and American College of Human Genetics.
- ○ Interface with public health programs (i.e., newborn screening and birth defects registry, Chronic Disease Service, Women's Health Service etc.), county health departments, and Children with Special Health Care Needs of Department of Human Services (DHS) to integrate genetics into these programs and provide education to program staff to improve surveillance and referral to clinical genetic services.
- ○ Establish relationships with programs that have not used genetic tools in the past, i.e., Chronic Disease, Acute Disease, and Environmental Health.
- ○ Collaborate with the State Epidemiologist on potential opportunities for local genetic epidemiological studies.

Objective 2 - The OSDH Genetics Program will establish system linkages to better serve children with special health care needs.

Action Steps (◇ symbol identifies prioritized action steps):

- ◇ Develop a system for integration of public health services through system linkages and adequate genetic program resources to ensure children with special health care needs are met (priority number 1).
- ◇ In collaboration with the Newborn Screening Programs and Pediatric Committee of OGAC, assure the medical home includes access to pediatric sub-specialty care (priority number 5).
- ○ Develop and promote the Family Health Services data integration plans to improve identification of children in need of genetic services by:
  - i. Continuing to implement the data integration of the Newborn Metabolic Disorder Screening Program and Newborn Hearing Screening Program, and Vital Records.
  - ii. Reviewing the feasibility of linking the newborn screening programs database with the Oklahoma State Immunization Information System (OSIIS).
  - iii. Reviewing the feasibility of linking the newborn screening programs database with the WIC and Lead Screening programs.
  - iv. Developing a data system for the long-term follow-up, to include links to the pediatric sub-specialist, of infants identified with a disorder through newborn screening.
  - v. Reviewing the feasibility of Web-enabled data system to improve follow-up of CSHCN to include linking and sharing information with the pediatric sub-specialist and medical home

- ○ Collaborate with the OSDH HIPPA representative to review access and release of information related to data integration efforts and program data, including newborn screening.
- ○ Promote a system of communication between genetic providers, pediatric sub-specialist, and the medical home to facilitate and ensure the needs of the child and family are met.
- ○ Collaborate and assure program linkages exist with Family Voices, Early Intervention, and CSHCN to ensure families of children with special health care needs are met.
- ○ Maintain CSHCN representatives (families and professionals) and other public health programs that serve CSHCN on the OGAC and Newborn Screening Programs and Pediatric Committee of OGAC.
- ○ Establish monthly or quarterly meetings between OSDH genetics program and the Department of Human Services CSHCN staff to identify opportunities to collaborate and share data on CSHCN population.
- ○ Collaborate with the Birth Defects Registry, Prenatal Screening and Diagnosis Committee of OGAC in assessing the feasibility of utilizing the birth defects registry to identify populations who would benefit from genetic services and establish a system to notify parents.

Objective 3 - The OSDH Genetics Program, in collaboration with OGAC and its committees, will assure that clinical genetic services are of the highest quality.

Action Steps (◇ symbol identifies prioritized action steps):

- ◇ In collaboration with the Evaluation Committee of OGAC, establish a system at the OSDH to monitor availability, quality, utilization, and accessibility of genetic clinical services, to include monitoring for health disparities (priority number 4).
- ○ In collaboration with the Public Health Policy Committee of OGAC, develop recommendations (standards) for:
  - i. quality genetic clinical services, including culturally sensitive issues, i.e., services are provided that are sensitive to the culture of the consumer.
  - ii. indications for referral to genetic clinical services