

## **Life Course Perspective**

Life Course Perspective concepts to guide planning:

- Each life stage influences the next and these composite experiences have a profound impact on health
- Health can be impacted by intervention at critical periods
- Biological, behavioral, psychological, social, and environmental factors contribute to health outcomes across a person's lifetime
- A wide range of conditions exist for which there are disparities across population groups that cannot be explained purely on the basis of differences in an individual's genetics, knowledge, behavior, or use of medical services

## **Strategic Framework**

In June 2010, a Genetic Services Branch (GSB) Strategic Planning Steering Committee was convened to advise GSB staff on the development of a framework that would provide a structure for the development of a ten-year strategic plan. The framework consists of a vision, mission, goals, and main topic areas for discussion.

**Vision: Genetic science is intrinsic to the understanding of health and wellbeing throughout the life course of an individual.**

**Mission: Provide national leadership to improve, expand, strengthen, and evaluate access to a system of genetic services and the quality of those services for children, youth and adults across their life course.**

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## **Creating a Strategic Plan for the Genetic Services Branch**

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### **GOALS :**

1. Translate genetic medicine into public health and health care delivery systems
2. Develop and sustain public health capacity in genetic services
3. Develop and sustain programs to engage families and the general public in partnerships about genetic service education programs

### **Main Topic Areas/Breakout Sessions**

#### **1. HRSA's role in delivering genetic services using a life course approach (Addresses Goal 1)**

*Charge: Identify and prioritize strategies to integrate and coordinate genetic information into health care and public health services throughout the life course*

#### **Things to consider**

- Develop and implement guidelines and standards for genetic screening and testing from birth through adulthood
- Use genetic information to reduce health disparities

- Integrate genetic information and counseling services within the limits of health care delivery systems
- Ongoing management and treatment through transition into adulthood for those diagnosed with a genetic condition through newborn screening
- Prenatal screening and counseling
- Screening and counseling for chronic disease
- Use distance technologies for delivering services (diagnosis, management and treatment)
- Improve communication between the specialty and primary care provider using electronic health record, long distance technology, and other advancing resources

## **2. HRSA's role in meeting state public health needs (Addresses Goal 2)**

*Charge: Identify and prioritize strategies to assist states in the delivery of genetics services to the whole population and work to improve outreach and follow up on those identified with an inherited condition*

### **Things to consider**

- Services for the whole population across the life course
- Policies and standards to ensure access to genetic testing and services while protecting privacy
- Surveillance and improved global screening implementation to identify those affected with inherited disorders
- For those identified with an inherited condition
- Financial support for these services that are often under or unreimbursed
- Health information exchange needs to communicate between public and private sectors of health care delivery
- The impact of health care reform and reimbursement for genetic services across the life course
- Establish between specialty and primary care provider, the evaluation of the quality of services to improve access, integration and coordination of services

## **3. HRSA's role in improving the genetic literacy of the public (Addresses Goal 3)**

*Charge: Identify and prioritize strategies to improve the genetic literacy of the public so they can make informed, quality decisions about genetic testing and services*

### **Things to consider**

- What the public needs to know to ensure they receive quality genetic testing, counseling and clinical services
- The public's readiness for incorporating genetics into their health care behaviors/seeking/decision making
- The value of educating the public about genetics in relation to state and national prevention and health care priorities, and state and national health policy discussion
- How messages should be formulated to meet the needs of/catch the attention of different audiences throughout the life course
- Relationship of genetic literacy goals with the health literacy agenda
- Dissemination methods of genetic literacy messages through new and novel partnerships

#### **4. HRSA's role in advancing the genetic literacy of providers (Addresses Goal 1)**

*Charge: Identify and prioritize strategies to improve the genetic literacy of clinical and public health providers so they will use genetic information and technology to improve the health of patients/the public*

##### **Things to consider**

How to:

- Develop and implement standards for knowledge needed by various types of providers as they serve patients/the public throughout the life course
- Implement the providers' inclusion of genetic information into everyday clinical practice
- Formulate and deliver messages about genetic education to engage and meet the needs of provider groups
- Educate providers on the importance of integrating family/patient-centered care using genetic information when appropriate