

## ABSTRACT

**Project Title:** Hawaii State Genetics Planning Project  
**Organization:** Hawaii Department of Health/Children with Special Health Needs Branch  
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**Project Director:** Sylvia M. Au, M.S., C.G.C., State Genetics Coordinator  
**Project Period:** June 1, 2000 to May 31, 2002

**Purpose:** The Hawaii Health Department's Children with Special Needs Branch is requesting funds for two years to expand the current genetics needs assessment and develop a revised State Genetics Plan.

**Problem:** Hawaii's Genetics Needs Assessment and State Genetics Plan were written in 1993 and we have accomplished many of the goals in the plan. However, due to our continuing economic recession, we have many program, budgetary, and legislative changes. A revised State Genetics Plan needs to be developed to address the many changes in our public health system during the past seven years, the Healthy People 2010 objectives, Council of Regional Networks for Genetics guidelines, and the new technological advances from the Human Genome Project.

### Goals and Objectives:

Goal 1) Expansion of our State Genetics Needs Assessment

- Objectives:
- (1) By September 1, 2000 have provider, consumer, and public health subcommittees review current needs assessment and make recommendations for the development of activities to obtain more detailed assessment information;
  - (2) By November 1, 2000 the plan for expanded needs assessment activities will be presented to the State Genetics Advisory Committee and available on the website for review and comment;
  - (3) By April 1, 2001 needs assessment activities will be completed;
  - (4) By April 20, 2001 needs assessment information will be analyzed and the report will be written and disseminated for review and comment; and
  - (5) By May 31, 2001, the final report will be published and disseminated.

Goal 2) Creation of a revised State Genetics Plan.

- Objectives:
- (1) By July 1, 2001 have outline of goals and objectives for state genetics plan developed from current state genetics plan, information from all genetic needs assessments and any other relevant guidelines and information. Emphasis will be place on activities to:
    - (a) Integrate newborn screening with early intervention programs including genetic services;
    - (b) Integrate genetics into all areas of public health especially in the area of chronic diseases;
    - (c) Increase the collaborative efforts between the Department of Health and private sector health care providers and agencies;
    - (d) Determine the feasibility of creating a community based child health profile;
    - (e) Increase consumer input for public health genetics activities;
    - (f) Link genetic services with the medical home that provides family centered, community-based, comprehensive, coordinated, and culturally competent care; and
    - (g) Provide genetics related education.
  - (2) By August 15, 2001 present outline to State Genetics Advisory Committee and the provider, consumer and public health subcommittees for review, comment and recommendations;
  - (3) By August 15, 2001 have outline available on our Department of Health website for public review and comment;

- (4) By September 15, 2001 create workgroups from membership of the State Genetics Advisory Committee, ad hoc subcommittees and other relevant experts to address the major priority areas identified.
- (5) By January 30, 2002 have workgroups present reports of their findings and recommendations at a public forum;
- (6) By March 1, 2002 have first draft of State Genetics Plan completed for review by State Genetics Advisory Committee, subcommittees and the general public. Draft plan will also be posted on the website;
- (7) By May 23, 2002 complete a satisfaction survey targeted to individuals who participated in the needs assessment and development of the State Genetics Plan process; and
- (8) By May 31, 2002 have final State Genetics Plan submitted to HRSA and disseminated to all interested parties.

**Methodology:**

- (1) Expanding the State Genetics Needs Assessment  
The project will contract with the needs assessment consultant. Results from our current preliminary genetics needs assessment and HRSA recommended areas of emphasis will be analyzed by the State Genetics Advisory Committee, the provider, consumer and public health subcommittees and the general public. All data, drafts and reports will be placed on the genetics section of the Department of Health website to allow public review and comment. The findings of the committees and comments for other interested parties will be used to determine which areas require a more detailed assessment of need for genetics services. The detailed needs assessment activities will be developed and implemented as determined by the existing advisory groups. Results from the preliminary and detailed needs assessments will be used to develop the State Genetics Plan.
- (2) Creation of a revised State Genetics Plan  
An outline of the goals and objectives for the State Genetics Plan will be developed from the current State Genetics Plan, all needs assessments, Healthy People 2010 Objectives, Council of Regional Networks for Genetics guidelines and HRSA recommendations. The goals and objectives will be presented for review and comment to the existing advisory groups and the general public. The State Genetics Plan will be developed from the needs assessments and any other relevant information. Drafts of the Plan will be presented to existing advisory committees and the general public for review and comment. A final State Genetics Plan will be disseminated to HRSA and all interested parties. A satisfaction survey will be provided to all individuals who participated in the project.

**Evaluation:**

The evaluation will include: (1) process evaluation of attainment of state goals, objectives and activities by stated dates; (2) Statistical analysis of the validity of the needs assessment results; (3) Provider, consumer and public health personnel satisfaction surveys.

**Text of**

**Annotation:**

The Hawaii State Genetics Planning Project is a collaborative effort to develop an expanded Genetics Needs Assessment and develop a revised State Genetics Plan.

**Key Words:** State Genetics Plan, Genetics Needs Assessment