

ABSTRACT OF FINAL REPORT

PROJECT IDENTIFICATION:

Project Title: The Michigan Genetics Plan: Assessment of Service and Infrastructure Needs
Project Number: 1 H46 MC 00174
Project Director: Janice Bach, MS
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Project Period: June 1, 2002 – May 31, 2003
(no cost extension of original project from 6/1/00 through 5/31/02)
Total Amount of Grant Awarded: \$14,297 (year 01 carryover from original \$150,000 award)

PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MCH PROGRAMS: The purpose of this project was to bring planning for a comprehensive state genetics plan for Michigan to an orderly conclusion, disseminate the results, and transition to implementation. Funding for the project was provided by the Maternal and Child Health Bureau/Genetic Services Branch in response to CFDA 93.11A—Planning Grants for State Newborn Screening Efforts and Infrastructure Development. The project strengthened awareness and linkages with Michigan Department of Community Health (MDCH) Title V Maternal and Child Health (MCH) programs including: early hearing detection and intervention, immunization, lead screening, maternal and infant support services, WIC, Women’s and Reproductive Health, Child Health, Pregnancy Risk Assessment and Monitoring System (PRAMS), and Children’s Special Health Care Services. In particular, the needs assessment process led to recommendations in the state plan that will improve Michigan’s newborn screening system and thereby directly address the national core performance measure relating to newborn screening.

GOALS AND OBJECTIVES: The original goal of the project was to develop a comprehensive state plan for public health genetic services that defines the priorities of Michigan residents representing a wide array of stakeholders throughout the life cycle. The genetics plan was developed and a final report for the original two-year project period was submitted to the Maternal and Child Health Bureau in August, 2002. Authorization for use of carryover funds and a no-cost project extension was requested and received. During the extended project period, particular emphasis was given to Objective #2: Identify available data sources and develop recommendations for integration of existing databases to enhance infrastructure and identify uses for these data related to creating a child health profile with emphasis on genetics case-finding and early intervention. In addition, the goal was to produce a printed copy of the plan, and disseminate information about the needs assessment process and resulting plan to interested parties within and outside the state of Michigan.

METHODOLOGY: The state plan for Michigan, *Genetics Through the Life Cycle: Improving Health and Preventing Disease*, is based on a statewide needs assessment and planning process conducted over an 18-month period from August 2000 through January 2002. A detailed description of the needs assessment methodology and project activities leading to development of the plan was previously provided. During the past year, further planning for data integration included an assessment of the suitability of existing medical management clinical databases for use in longterm newborn screening follow-up. Design and layout for the printed version of the plan, along with an executive summary pamphlet, were finalized. Information about the needs assessment process and state plan was disseminated at a national conference and to audiences within the state.

EVALUATION: The key measure of success was production of a state plan that was endorsed by community stakeholders and MDCH administration. The additional database work will

support better longterm evaluation and monitoring of certain genetic health status indicators related to preventive health care as well as morbidity and mortality in children identified through newborn screening. These measures will be used to monitor portions of the plan being addressed through a recently funded HRSA implementation grant.

RESULTS AND OUTCOMES: Considerable progress was made in preparing existing clinical databases for use by MDCH staff to provide longterm tracking and follow-up of children diagnosed with metabolic and endocrine diseases. The medical management clinics will be asked to provide follow-up data directly to a new NBS laboratory database after it becomes operational in October, 2003. Collaboration and integration with the Michigan Childhood Immunization Registry was strengthened and a working group was established to pursue development of a web-based integrated child health system. Information about the needs assessment and state plan was shared with numerous interested parties and stakeholders.

PUBLICATIONS/PRODUCTS: The primary product is a printed copy of the state genetics plan and an executive summary pamphlet that are also available as pdf files. Other products include a poster describing the needs assessment process and state plan goals, as well as PowerPoint slides used to share information during presentations.

DISSEMINATION/ UTILIZATION OF RESULTS: A poster was presented at the 2002 Annual American Public Health Association Meeting and Exposition. Presentations about the needs assessment and state plan were also given at the annual state genetics symposium, at the Michigan Cancer Consortium annual conference, and at a series of trainings for Maternal Support/Infant Support Service Coordinators. A poster display summarizing the needs assessment findings regarding genetic literacy was presented at the Michigan Science Teachers Convention, and a presentation on data use for genetics and newborn screening program planning, service delivery and evaluation was provided at the annual Michigan Information

Integration Conference for Public Health. The needs assessment, state plan and newborn screening program were also highlighted during an MDCH open house event titled, DNA Day: A Celebration of Genomics and Public Health, which provided an opportunity for colleagues to learn more about the genetics and newborn screening programs. Copies of the plan are being distributed to advisory committee and working group members, and a pdf file will be placed on the MDCH website.

FUTURE PLANS/FOLLOW-UP: As a result of increased awareness generated by the planning grant, the genetics/newborn screening program has been integrated into ongoing discussions regarding development of a web-based child health information system. Successful completion of the planning process also led to a HRSA-funded grant for implementation of selected state plan objectives, now in its second year. The plan will be used as a blueprint for program activities over the next five years, and relevant excerpts will continue to be highlighted with various audiences around the state as opportunities become available to attend conferences, give presentations and meet with partner organizations and stakeholders.

TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE: Carryover funds in the amount of \$14,297 were used to enhance data integration and initiate dissemination activities. This included funding for contractual staff to prepare existing clinical databases for integration with public health systems; prepare, produce and present a poster; and design and print hard copies of the state plan, along with an executive summary pamphlet.