Abstract Of Final Report

Project Title: South Alabama Integrated Health Services for Genetic Conditions

Project Number: 1 H46 MC 00165-01

Project Director: Wladimir Wertelecki, M.D.

Grantee Organization: Alabama Department of Rehabilitation Services

Address: P.O. Box 11586, Montgomery, Alabama

Contact Person: Steve Shivers, Commissioner

Phone Number: (334) 281-0780

Fax Number (334) 281-1973

E-mail Address: sshivers@rehab.state.al.us

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Total Amount of Award: $514,382

PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS: Birth defects are the leading cause of infant mortality. The purpose of this project is to demonstrate improvements in the integration of health services, in a three county area, for infants and young children with spina bifida, facial clefts, and multiple congenital anomalies identified through a birth defects surveillance system.

GOALS AND OBJECTIVES: The Project will demonstrate an improved health services delivery system for children with spina bifida, facial clefts, and multiple congenital anomalies by mainstreaming genetics knowledge, linking children to medical homes, and use of technology to remove barriers to access to care. Standards will be developed for tracking and follow up through a database system containing all pertinent information needed to measure the morbidity and mortality of infants enrolled in the project.

METHODOLOGY: An Advisory Committee was formed to develop a common vision. Surveys were administered to identify barriers to care which were addressed by various means throughout this project. In-services were held to enhance early identification and enrollment in the project. Cultural competency of health care providers was assessed and training was completed.

EVALUATION: Family satisfaction surveys and a clinical database were designed to evaluate improvement in access, compliance with therapies, and satisfaction with services provided.

RESULTS/OUTCOMES (POSITIVE & NEGATIVE): There was an overall decrease in non-compliance in the current cases due

to early identification and case management by the CRS project nurse. There was a significant decrease in non-compliance in mothers under the age of 21. There was an increase in recruitment of culturally and ethnically diverse populations to serve on both the local parent advisory council and the Advisory Committee. Parents and medical homes expressed positive feedback in the use of the Parent Journal.

PUBLICATIONS/PRODUCTS:Products developed include: a Parent Journal with an evaluation form, a resource notebook, a project brochure, several barriers to care surveys, a family satisfaction survey, various fact sheets for families and a clinical database.

DISSEMINATION/UTILIZATION OF RESULTS: This project was chosen for poster presentations at three National Birth Defects Meetings. The Parent Journal has been distributed at various clinics and early intervention sites, at health fairs, at national meetings, and is also available on the Internet.

FUTURE PLANS/FOLLOWUP: We plan to continue to offer the Parent Journal to families of children with special health care needs through various clinics and community outlets as

well as on the Internet. An agreement has been signed between our team and state agencies to link birth defect surveillance and early intervention services.

TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE: The process and products of this program are highly adaptable to other settings. We feel a 1.0 Genetics Nurse would be able to evaluate the program and make the necessary modifications to produce documents, processes and procedures that would be best suited for use in his or her specific environment and to maintain the program on a daily basis.

ANNOTATION: The purpose of this project was to demonstrate improvements in the integration of health services, in a three county area, for infants and young children with spina bifida, facial clefts, and multiple congenital anomalies by mainstreaming genetic knowledge, linking children to medical homes, and use of technology to remove barriers to access to care. Barriers to care were identified through survey instruments developed by grant personnel and resulted in the creation of a Parent Journal, a resource notebook, medical information fact sheets, individualized preventive genetic plans, in-service training for hospital personnel regarding early identification and referral to appropriate services, state-wide cultural competency training for health care providers, and the development of a client database to measure morbidity and mortality.

KEY WORDS: Advisory Committee; Barriers to Care; Birth Defects Surveillance; Care Coordination; Cultural Competency; Early Identification; Early Intervention; Educational Material; Facial Clefts; Individualized Preventive Genetics Plan; Medical Genetics; Medical Home; Multiple Congenital Anomalies; Nurses; Parent Connection; Parent Journal; Resource Notebook; Spina Bifida.