

FINAL ABSTRACT

Project Title: Puerto Rico CISS/COG Project to Enhance Managed Care Systems / Puerto Rico Medical Home Project
Project Number: H25MC00178
Project Director: Naydamar Perez de Otero, MD.MPH.
Grantee Organization: Puerto Rico Department of Health
Division of Habilitation Services
Address: PO Box 70184
San Juan, Puerto Rico 00936
Phone Number: (787) 274-5660
E-mail Address:
Project Period: 7/01/00 to 01/31/03
Total Amount of Grant Awarded: \$149,956.00

PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS: Puerto Rico has a large number of CSHCN who do not have a medical home and we can say that families and health care providers may not have an appropriate understanding of the core elements and principles of the medical home concept. The purpose of the Division of Children with Special Needs in Puerto Rico for this initiative was to divulge the concept of accessible, comprehensive, family-centered, continuous, coordinated, compassionate, well coordinated, and culturally effective care for children with special health care needs and to develop infrastructure for the support of the concept. Through this project we moved towards enhancing the capacity of all players involved in the delivery of care (i.e., parents, primary care providers, MCOs, and private agencies) planning, developing, implementing, tracking and evaluating the medical home concept of quality care.

It is important to take into account that in Puerto Rico the formal mechanism of the Health Care Reform System (capitated managed care), which allows almost every low income family in the Island to have access to primary care services, does not guarantee that: 1) each CSHCN will have access to a pediatric medical home; 2) there are clear mechanics to identify, monitor and track this population; and 3) that all families of CSHCN as well as health care providers will be trained and educated regarding the basic components and the benefits of pediatric medical home.

The Puerto Rico Medical Home Project provided an opportunity to address access and quality issues of the health care reform. With the Medical Home project we accomplished several important achievements. A Planning Committee was established to advise the project coordinator and DHS staff, created awareness and celebrated educational activities that took

place in the seven health regions with parents and physicians from the Pediatrics Centers as resources and presenters. We also adapted and translated educational material and a training module, performed promotional activities and developed strategies aimed at the compliance with phase I of the pilot study to identify children with special health care needs who received services at the pediatrics centers and who have a medical home. During phase I of the pilot study, the activities were addressed to organize a collaborating committee and evaluation of the instruments; definition of the universe; sample selection and validation of the instrument. We were also interested in “care coordination for CSHCN” a service that is recognized as an essential core activity in supporting medical homes practice models. The Title V CSHCN nurses providing care coordination at the pediatric centers participated in the training and are closely collaborating to create awareness and educate families about the benefits of services within a medical home. Future areas of collaboration include the training of these providers to evaluate the cost of providing care coordination to families enrolled in a medical home practice.

GOALS AND OBJECTIVE: To divulge the Medical Home concept it is necessary to initiate an educational process for parents, providers, health insurance representatives and Pediatrics Centers Staff. For this reason our first goal was related to the education: “To educate and empower families and service providers of CSHCN about the medical home concept following the Title V principles”. The objectives for this goal were: “To determine the number of CSHCN under 21 years of age and their families in Puerto Rico who have a medical home; to educate 20 primary care providers and 20 families from each of the Pediatric Regions about the medical home concept and to educate health care providers from both public and private agencies”. The second goal was related to developing infrastructure for the support of the concept: “ To develop a data tracking system that will allow us to register and monitor all CSHCN with a medical home”. The objectives for this goal were: “to determine which data tracking systems are available in Puerto Rico, which can be modified to follow a population of CSHCN; to evaluate existing data tracking systems by adding the medical home data and to modify identified data tracking systems to incorporate the recommended changes”.

METHODOLOGY: In order to meet its main goal, the Puerto Rico Medical Home Project revised the training curricula of the AAP and prepared a culturally appropriate training manual in Medical Home and an educational brochure with the key components of the medical home concept. After the revision and adaptation of the AAP training curricula, the project

implemented a total of seven (7) regional trainings using the “train the trainer” approach. These trainings impacted a total of 556 participants, including Pediatric Centers service providers, community providers, and families. As a result of the training sessions, a total of 16 families and 17 physicians participated as resources to provide training and information at a regional level. Another strategy used to meet the established goals were the coordination and celebration of the First Medical Home Conference and the participation of the medical home coordinator and trained physicians in the Puerto Rico Pediatricians AAP Chapter Annual Meeting.

In order to attain the second purpose of the project, to increase the number of CSHCN in Puerto Rico who have a medical home, the project staff performed an identification and adaptation of medical home assessment tools. The project developed a culturally appropriate set of medical home assessment tools that include a Spanish version of the Living with Illness and the Family Assessment Tools for Medical Home designed by the AAP. Finally, a collaborative effort has been developed with the Medicaid Program in order to identify the CSHCN in Puerto Rico and the Pediatric Center Information System will include an electronic field to record and track the medical home status of the children served at the centers.

EVALUATION: The evaluation process of this project was focused on measuring the indicators to determine that the established goals and objectives were attained. During the first phase of the project, the staff identified and developed culturally appropriate instruments to assess the knowledge and the medical home status of CSHCN in Puerto Rico. The customized instruments were used to establish a baseline regarding the medical home status and the knowledge level of families and of health care service providers. All educational and training events were evaluated in terms of quality and usefulness, among other aspects. At the end of each project year, the project staff performed a survey to determine the number of children who have a medical home and any changes/improvements in the level of knowledge among families and health care providers. In addition activities logs, registrations lists and brief evaluations based on quality indicators and performance standards were used to collect data on the progress of the project.

RESULT / OUTCOMES: One of the major accomplishments for the Puerto Rico Medical Home Project was to establish a Planning Committee with parents as members, primary providers, physicians, medical specialists and Pediatric Center staff. The planning committee also collaborated by adapting and translating educational material, training modules, and assessment tools considering cultural appropriateness. The First Annual Conference of Medical Home,

which took place in 2001 was another major accomplishment. Over 200 people attended the conference including parents, primary physicians, community agencies, and Pediatric Centers staff. Seven training sessions were performed, one in each of the seven health regions with the participation of 556 people during the year 2002. Different activities were performed as part of the pilot study including: organization of a committee (evaluator, epidemiologist, LAN, administrator, director, deputy director), evaluation of the instrument; definition of the universe; sample selection and validation of the instrument. A collaboration with the Medicaid Program is in place to identify CSHCN in Puerto Rico who apply for the health care reform card. The Pediatric Center Information System was evaluated and modified to include a field that registers the medical home status of the children receiving services at the centers.

PUBLICATIONS / PRODUCTS: The Project designed and prepared a brochure, translated to Spanish and adapted other materials and training module including four assessment tools developed and validated by the AAP. Audiovisual material is available for providers upon request.

DISSEMINATIONS / UTILIZATION OF RESULT: Health Care providers and families now have an educational brochure, training module, special audiovisual material that is available for the use of those interested in creating understanding and awareness about the concept. The committees will continue working to expand the medical home concept within the island.

FUTURE PLANS/ FOLLOWUP: Identify physicians or mentors at each health region willing to establish a Medical Home for CSHCN and to be educated about providing appropriate family-centered services, care coordination and medical record documentation. Continue the pilot study to determine the number of children with a Medical Home training parents as interviewers to perform the survey. Also design a new brochure about the concept of medical home for parents. Develop closer collaboration efforts with the Puerto Rico AAP Chapter to promote the medical home approach among service providers. Meet with health reform representatives and health insurance agencies need to further awareness and growth of the Medical Home Initiative.

TYPE / AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE: The Early Child Comprehensive System Grant (ECCS) will provide an excellent opportunity to continue collaboration between Title V, the health insurance agencies, providers, community agencies and families towards further development of regional support, awareness, education and therefore identification of community providers of medical homes.

ANNOTATION:

Puerto Rico has a large number of CSHCN who do not have a medical home. Families and health care providers may not have an appropriate understanding of the core elements and principles of the medical home concept. Our Division will continue to educate and empower families and service providers of CSHCN about the medical home concept and develop a data tracking system to register and monitor all CSHCN with a medical home. In order to reach our goal we will work on the following: Planning Committee, educational activities, promotional activities, interagency collaboration, community providers, culturally appropriate material and practices and continue with the pilot study.

KEYWORD:

Access to health care

American Academy of Pediatric

Children with special health care needs

Chronics illnesses and disabilities

Community Integrated Services Systems

Data collection

Data systems

Early Intervention

Family centered services

Health care reform

Managed care

Medical home

Minority groups

Professional education in MCH

State Health Agencies

Planning Committee

Family Integration

Quality health services

Advocacy

Family Support Services

Health Promotions

Puertorricans

Educational & Material Activities

Culturally competent & effective

Accessible

Family centered

Continuous

Comprehensive

Coordinated

Compassionate

Childhood

Initiatives

Training Program

Participation

Family empowerment