

Project title: Practice Based Community Connections (PBCC) (CISS-COG)  
Project number: 1 H25 MC 00212-01  
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Total amount of grant awarded: \$50,000

PURPOSE OF PROJECT: “Children with special health care needs [CSHN] are particularly vulnerable to service fragmentation, financial barriers, and the acute care orientation of the health care system.... The historic lack of coordination between medical, social services, mental health and educational systems, coupled with a pattern of categorically funding services as opposed to meeting the needs of the whole child, has tended to lock families their special needs children into a world...[of] confusion, frustration, and limited opportunities.” *1997 Oregon Health Plan Parent Satisfaction Survey*.

Families of CSHN often need community services (social, respite, recreational and educational supports) in addition to health care services. These non-medical supports and services have a major impact on the wellness of the child with special health needs. Due to a lack of communication among the health, education and social service organizations, families must often act as messengers, translators. Families cannot always serve their child in these roles, thus compromising the child’s access to services.

In 1991, through funding from the Bureau of Maternal and Child Health (MCHB), the Community Connections Network (CCN) was launched to develop a system of multi-disciplinary community-based teams to plan for the health, education and social concerns of CSHN (age 0 to 21 years) in rural Oregon. The 1994 advent of Oregon’s Medicaid managed care program had a significant impact on medical care for CSHN. The 1997 Title V Needs Assessment of CSHN identified major problems: less than 50% of the parents participated in a partnering relationship with their child’s health care providers; only 40% consistently received meaningful and complete information about their child’s

condition; and less than 50% have a consistent trusting relationship with their child's health care providers. Primary care physicians (PCPs) may not understand how non-medical supports are used or funded, especially when they have to deal with multiple Managed Care Organizations (MCO's) and ever-changing public resources. Since the change to managed care, CCN has worked to promote partnerships with MCO's across the state. MCO's are beginning to understand the extra time and resources needed, but increased awareness has not yet translated into provider reimbursement for the enhanced care coordination time needed for CSHN.

**GOALS AND OBJECTIVES:** In this project the CCN model was used in a private practice setting, and a Medicaid MCO's case manager was named to the team. It was hoped that this inclusion would lead to reimbursement for care coordination services.

The goal of this project: to improve the ability to solve complex medical issues for children with special health care needs within a managed health care system by exploring partnerships with the child's primary care practice, MCO, parents, state and community resources. To accomplish this goal the objectives included:

1. Demonstrate an effective team model for managing care of CSHN in a PCP office
2. Improve communication between PCPs, families, specialists, MCO's and other health and service providers involved in the child's care
3. Organize community-based resources and supports for families
4. Create better systems for identifying CSHCN, evaluating outcomes, and improving quality within the collaborating MCO.

**METHODOLOGY:** In the first nineteen months of this project, a physician and office nurse/care manager from the practice, a mentor parent coordinator, and a case manager

within the major Medicaid MCO were identified. The physician, nurse and mentor parent received training around the Medical Home concept and coordinated care for CSHCN. Monthly care coordination meetings for patients and their families within the practice were held, connecting families with the medical/community resources needed to optimize health. Utilization, outcome, cost and satisfaction data were collected.

EVALUATION: The effectiveness of the PBCC project has been evaluated both locally and at the program level utilizing both outcome and process indicators. Indicators include the results of our “Parent Evaluation” instrument given to families on the day of their clinical experience with the team, as well as a phone survey conducted three months after the clinic experience. Training efforts (numbers served, topics, presenters) including community consultations and annual statewide training are evaluated.

RESULTS/OUTCOMES: The advent of managed health care has had a negative impact on aspects of the relationship between families of CSHNs and their child’s PCP. Time spent/fiscal reimbursement for a single clinic encounter no longer allows adequate time for the primary care provider to provide care coordination help or to learn about/educate patients and families about community resources. MCO’s need more education about the need for care coordination for CSHN, and the need to reimburse physicians and/or their staff to provide it. This project created a venue for a comprehensive evaluation of a child with special health needs, bringing together different professionals involved in the child’s life and the child’s family, where recommendations could be coordinated in a seamless manner. It is most gratifying that the PBCC team has been incorporated into the existing network of multi-disciplinary teams across the state (CCN), a program funded by MCHB block grant to Oregon. It was disappointing that representation from the managed care

organizations were not able to participate more actively. During the course of this project 13 children were evaluated and staffed (11 Caucasian, 2 Hispanic) problem-solving around issues of behavior, learning, feeding and service coordination. 4 professionals each received 2.5 days of training each year. Parent evaluation results (phone survey) were favorable. All families felt that PBCC team recommendations had been at least “partially” implemented at the time of the 3- month follow-up call. All families felt they had ample opportunity to express their needs at the meeting and were “satisfied” to “very satisfied” with their level of involvement.

**PUBLICATIONS/PRODUCTS:** There were no publications or products.

**DISSEMINATION/UTILIZATION OF RESULTS:** Parent and training evaluation results are disseminated annually to the team. As the State CSHN agency, the Child Development & Rehabilitation Center (CDRC) is knowledgeable about the success and difficulties in implementing this project through the normal reporting procedures already in place for the CCN. They are included in the annual Title V Block Grant report that is disseminated regionally and nationally.

**FUTURE PLANS/FOLLOWUP:** The PBCC team has been incorporated into CCN, a program funded by the Maternal & Child Health Bureau block grant to Oregon.

**TYPE/AMMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE:**

Local Coordinator: \$8544/year, Physician time: \$5200/year, books and supplies

\$200/year, travel and training \$500/year