AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS
Innovation Station
Sharing Best Practices in Maternal & Child Health

Care Connection for Children

Location: Virginia
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Category: **Emerging Practice**

TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED
#11 Percent of children with and without special health care needs having a medical home **#12: Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care**

BACKGROUND

Approximately 19 years ago, the VDH Children and Youth with Special Health Care Needs (CYSHCN) program went through a partial restructure and transformed Children's Specialty Services (CSS) to the Care Connection for Children Program (CCC). This transition was based on a study commissioned by the Virginia Department of Health and the evolving vision of Title V at the time. CSS was a program that focused mostly on clinical services that were provided at local health departments. Since these services were routinely being provided elsewhere (at major pediatric health care systems), VDH decided to transform the CSS to a care coordination based program and the CCC was born.

The study that informed this decision involved the establishment of an advisory task force charged with overseeing the projects stated goals. Members of the task force included parents, primary care/specialty pediatricians, public health nurses, early intervention and special education providers, representatives from private and public insurance providers, and several state agencies. Approximately 40 people were on the task force. In its current form, the Virginia Care Connection for Children (CCC) Program provides care coordination services for special needs children who have a condition that is of a physical basis. Services are provided in partnership with major medical centers across the state.

PROGRAM OBJECTIVES

The goal of the CCC program is to improve health outcomes for the CYSHCN it serves by:

- Helping families attain and maintain a relationship with a medical home to include specialty provider care;
- Assisting with the transition from pediatric to adult care and life by working with families to prepare for transition;
- Serving as a safety net to provide durable medical equipment, pharmaceuticals, and specialty copays as a payer of last resort;
- Helping families to understand their health insurance benefits and to apply for Medicaid and;
- Helping families to understand their child's condition and any recommendations from practitioners.

TARGET POPULATION SERVED

Children are eligible for care coordination services if they are residents of Virginia, between the ages of 0-21, and have a condition that is physical such as cystic fibrosis or diabetes. The program does not provide care coordination for conditions such as asthma, allergies, or diseases where families can generally get services elsewhere (cancer, HIV/AIDS, hemophilia).

PROGRAM ACTIVITIES

Activities include care coordination such as working with families to attain adequate insurance, assistance finding specialty providers and understanding treatment plans, help finding resources to pay for medication and durable medical equipment and providing general information and referral services.

PROGRAM COST

The program budget is roughly $4.5 million. Out of this amount, approximately 80% or a little over $3.5 million is spent on staff salaries (nurses, social workers, parent

coordinators, administrative staff, center directors, and medical consultants). The remaining 20% or about $1 million is spent on pharmaceuticals, office supplies, travel, training, durable medical equipment, physician copays, and other related expenses.

ASSETS & CHALLENGES

Assets
One of the core strengths of the program is the partnership that the Virginia Department of Health (VDH) maintains with major pediatric health care systems across the state. There are six regional centers and all of them are managed via contract. This is an asset because each center represents a health system where CYSHCN can receive care coordination and clinical services from the same entity. The expertise of staff is another asset. Staff members are mostly composed of licensed RN's although several centers do employ social workers as care coordinators. In addition, the program employs office support staff and parent coordinators. This diverse staff of professionals is able to offer clinical support, social support, and parental support all via the CCC program.

Challenges
Cost of the program.

Overcoming Challenges
Staff are currently working with other organizations to diversify program funding.

LESSONS LEARNED

From the beginning, the program should have worked to form a partnership with Medicaid and the health systems to help support the work financially.

FUTURE STEPS

Future steps include the diversification of funding, more intensive evaluation of the services provided, and continued efforts to strengthen partnerships with external organizations.

PROGRAM OUTCOMES/EVALUATION DATA

The program conducted an extensive parent survey in 2013. The goal is to repeat this survey every 5 years. Results have been very positive. The 2013 analysis showed that parents are better able to do the following because of the CCC program:

- 65% said that they were better able to prepare their child for adulthood;
- 65% said they have been better able to pay medical costs;
- 68% said they were better able to get support for themselves (respite);
- 71% said they were better able to understand health insurance benefits;
- 73% said they were better able to get or keep health insurance;
- 77% said they were better able to get educational services for their child;
- 79% said they were better able to coordinate services among different providers;
- 82% said they were better able to get equipment or medical supplies;
- 82% said they were better able to get basic or primary care;
- 83% said they were better able to get prescription medications;
- 84% said they were better able to get medical care from a specialist
- 88% said they were better able to get answers to questions about their child's health and health care services.

COLLABORATIONS

The program partners with five medical systems throughout the state of Virginia and they include:

- Carilion Health System;
- Children's Hospital of the Kings Daughters;
- INOVA Health System;
- University of Virginia Health System and;
- Virginia Commonwealth University Health System

In addition, the program has a very strong partnership with the Virginia Department of Education, and family organizations (Partnership for People with Disabilities at VCU that houses Family 2 Family).

PEER REVIEW & REPLICATION

N/A

RESOURCES PROVIDED

A key resource for the Virginia CCC and CYSHCN program is the National Standards for Systems of Care for CYSHCN. It can be found at: http://www.amchp.org/programsandtopics/CYSHCN/projects/NationalStandards/Pages/default.aspx. To learn more about the Virginia CCC please click here: http://www.vdh.virginia.gov/care-connection-for-children/.

Key words:

Care coordination, case management, Children and Youth with Special Health Care Needs, disability.

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