

Partners in Care: Together for Kids

Location: Florida

Date Submitted: 2006, updated 6/2011

Category: **Emerging Practice**

BACKGROUND

Due to advances in technology and early screening, children with life-limiting conditions are living longer and often times are not receiving comprehensive health care to meet their physical and emotional needs. In July 2005, Florida's Partners in Care (PIC) program for children with life-limiting illnesses was created. Prior to the establishment of the PIC program, children with life-limiting illnesses received hospice care under the Medicare model. Because the life span of a child with a life-limiting illness is difficult to predict and the specific factors associated with childhood illnesses may require treatment up to the time of death, the Medicare model of hospice care is inappropriate for a pediatric population.

PIC is the first publicly-financed health program for children in the nation that utilizes a pediatric palliative care model which integrates palliative with curative or life-prolonging therapies. PIC is based on the Children's Hospice International Program for All-Inclusive Care for Children and their Families national model of pediatric palliative care which strives to provide a "continuum of care for children and families from the time that a child is diagnosed with a life-threatening condition, with hope for a cure, through the bereavement process, if cure is not attained".

The Florida Department of Health's Children's Medical Service Network (CMSN) has partnered with the Agency for Health Care Administration and Florida Hospices and Palliative Care to develop and implement this pediatric palliative care program.

PROGRAM OBJECTIVES

The overall objectives of this program include:

- Enabling children with potentially life-limiting conditions and their families to access a support

TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED
#11: Percent of children with and without special health care needs having a medical home.
#15: Percent of children 0 through 17 years who are adequately insured.

system that is continuous, compassionate, comprehensive, culturally sensitive and family centered from the point of diagnosis, with hope for a cure, through the provision of end of life care if needed

- Identifying and removing barriers that prohibit access to pediatric palliative care that is a compassionate, comprehensive, coordinated blend of services that support both curative and comfort care while preserving the quality of life for children with potentially life-limiting conditions
- Supporting families and caregivers of children with potentially life-limiting conditions.

TARGET POPULATION SERVED

This program is targeted to Children/adolescents who are 0-21 years of age, enrolled in the CMSN under Medicaid or CHIP (KidCare). Each participant must be certified annually by their primary care physician to have a life threatening condition.

PROGRAM ACTIVITIES

PIC offers a variety of services, which include the following:

Support Counseling

Spiritual support counseling is included in this service if requested by the child, family or caregiver. This service may be provided face- to-face in any setting the family request.

Bereavement Support Counseling

This service is provided for one year beginning at the time of the child's death. Services are to be provided by a hospice-qualified practitioner trained and experienced in support counseling for pediatric loss.

Activity Therapy (Healing Arts) (Expressive Therapy)

This service includes music, art or play therapies. These services are not for recreation but for therapeutic care and support of the child with a potentially life-limiting condition.

Pain and Symptom Management

This service provides physician consultation for pain and symptom management. A licensed, Medicaid physician who has documented expertise, training or certification in pediatric palliative care must provide the service.

Respite Care (in-home or in-patient)

The purpose of this service is to allow family/caregiver to take time out from their caregiver duties with a level of comfort that will allow them to restore their caregiver abilities. Respite is an alternative to hospitalization.

Hospice Nursing Care

This specialty service is to be used for assessment and medically necessary in-home nursing when the experience, skill, and knowledge of a trained pediatric hospice nurse are justified.

PROGRAM OUTCOMES/EVALUATION DATA

At the end of state fiscal year 2010-2011, 544 children were enrolled in PIC-Together for Kids (TFK). Of those, 90% had Medicaid coverage, 5% CHIP/KidCare, and 5% were in the Children's Medical Services Safety Net.

During 2010-2011, 169 PIC parents completed a survey to assess their opinions and satisfaction with the program. The parent surveys show that the majority of PIC:TFK families (92%) were very satisfied or satisfied with the program benefits and 87% reported the overall quality of care to be excellent to very good. Furthermore, high percentages of parents report that the PIC team is knowledgeable and helps to obtain answers to their questions.

PROGRAM COST

This program was implemented in July 2005 and is ongoing. There are thirteen operational sites with expectations that this number will continue to increase so that all 67 Florida counties will have PIC Programs by 2012. This program is funded through Medicaid (program costs were not provided). Please contact Florida Medicaid for additional funding information

ASSETS & CHALLENGES

Assets

- The CMSN provides a solid infrastructure to provide PIC services.

Challenges

- Diagnoses of the children in PIC can vary widely.
- Specific barriers to accessing services exist, such as families' lack of awareness about the program and confusion about the services provided.

Overcoming Challenges

- Recommendations were proposed that directors at each site review the primary and secondary diagnoses codes from the other sites to make sure that diagnosis are consistent.
- Participating parents suggested that at each program site a parent representative should be made available to speak with potential families to share their experience and provide useful information.

LESSONS LEARNED

- Identifying potentially eligible children is essential for providing services to the maximum amount of children in need and should not be seen as a tedious or unimportant task.
- It is recommended that all program materials be translated into appropriate languages for specific populations and that cultural competency is emphasized to all stakeholders. PIC outreach materials have been translated into Spanish and Creole.
- Family physicians should also be encouraged to take a larger role in identifying eligible children for the program.
- Is important to reach out to the community so that families are aware of the services provided.

FUTURE STEPS

The program contracts with the Institute for Child Health Policy (IHP), University of Florida to conduct annual satisfaction surveys of parents of PIC enrollees, as well as evaluation of all data collected. PIC continues to work with IHP to maintain those evaluations.

The PIC program is available in the majority of Florida's 67 counties and it is anticipated the entire state will have PIC coverage by the end of 2012.

COLLABORATIONS

Florida Hospices and Palliative Care, Inc. (FHPC) and the Department of Health, Children's Medical Services Network (CMSN) collaborated to form a partnership to develop the Program for All Inclusive Care for Children (PACC) grant proposal. Year one of the grant was dedicated to the development of a mutually agreeable PACC model that would meet Florida's needs and support the PACC model. The efforts of the workgroup resulted in the creation of the Florida PACC model called, Partners in Care-Together for Kids Program (PIC-TFK). This collaborative effort continues as the program expands statewide.

PEER REVIEW & REPLICATION



Neither peer review or program replication was cited in the application.

RESOURCES PROVIDED

For a complete report on this program, visit:

www.ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/annual_report_2007-08.PDF

Key words: CSHCN, Palliative Care, Respite Care
Children’s Medical Service, Medicaid

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