

Children's Medical Services Network

Partners in Care : Together for Kids

2006 - 2007



Institute for
CHILD HEALTH POLICY
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1 Executive Summary

BACKGROUND AND PURPOSE

In July 2005, Florida's Partners in Care: Together for Kids (PIC:TFK) program for children with life-limiting illnesses began.

Prior to the establishment of the PIC:TFK program, children with life-limiting illnesses received hospice care under the Medicare model. Designed for the elderly, the Medicare model of hospice care requires a patient to be in the last six months of life to receive hospice services and the patient must forego any curative treatments. 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:TFK is the first publicly-financed health program for children in the nation to utilize a pediatric palliative care model which integrates palliative with curative or life-prolonging therapies.

PIC:TFK is operated under the authority of the Children's Medical Services Network (CMSN). The CMSN is Florida's Title V program for Children with Special Health Care Needs (CSHCN). Children must be clinically and financially eligible in CMSN to enroll in PIC:TFK. Children enrolled in the program must represent all stages of illness: 1) newly diagnosed with a life-limiting condition, 2) mid-stage of their illness, which means that active treatment with life-prolonging or potentially curative treatments is provided, 3) end-stage where treatment options have failed. The goal is to have children approximately, equally distributed

across these illness stages at each pilot site. Formally, PIC:TFK is a pilot program operating in seven sites across the state: Pensacola, Jacksonville, St. Petersburg, Gainesville, Ft. Myers, West Palm Beach, and Miami.

The following services are included in the program:

- art, music, and play therapies
- pain and symptom control
- in home nursing
- in home personal care
- respite care
- counseling, and
- bereavement counseling

The federal Centers for Medicare and Medicaid Services (CMS) approved the PIC:TFK program as a 1915(b) Medicaid waiver program in 2005. As a result, the State was charged under federal guidelines with conducting an Independent Assessment (IA) of the PIC:TFK program. The Institute for Child Health Policy at the University of Florida (the Institute) is conducting the assessment.

DATA SOURCES

Three data sources are used in this report. First, each PIC:TFK site submitted monthly enrollment data throughout the 2006-2007 contract period. Second, a hospice survey was sent out and responses were collected by email about operational practices, standards of care, and procedures. Finally, survey data were collected via telephone and in-home. Survey data were collected for parents, children, and parents whose children died or were disenrolled from the program.

At a Glance

The purposes of this report are to:

- Describe enrollment from July 2006 to January 2007
- Describe results from a hospice administrator survey
- Describe results from a parent survey
- Describe results from a child/adolescent survey

KEY FINDINGS

Key findings from this study were:

- Enrollment is steadily growing but still about 70% below capacity. Barriers to enrollment need to be addressed.
- Parent surveys revealed that about 69% of families are very satisfied with their PIC:TFK nurse or therapist and 86% are very satisfied to satisfied with the PIC:TFK program benefits.
- PIC:TFK children had lower physical functioning skills

(composite score of 32) than emotional, social, or school functioning scores (61, 52, 49, respectively) on a scale of 0 to 100. However, the children's overall health-related quality of life scores are low.

- Seventy-five percent of PIC:TFK parents had current symptoms of depression (composite scores greater than or equal to 16).
- Families' experiences with doctor communication, shared decision-making, getting needed information, care coordination, and having a personal doctor or nurse were all positive with scores of 78 or higher on a scale of 0 to 100.
- Nine child surveys showed that children eight years and older were able to understand and answer the survey questions about their health-related quality of life.
- Parents with children who disenrolled from the PIC:TFK program were surveyed. The reasons for leaving the program were (in descending order): loss of eligibility, moving out of the service area, death, and transfer of child into a long term care facility.
- One hundred percent of the parents of disenrolled children who were surveyed were satisfied to very satisfied with the PIC:TFK program.
- Service use for the surveyed parents of disenrolled children was similar to the actively enrolled children with support counseling and nursing care being the services used most often.

- None of the PIC:TFK sites had 33% of their enrollees in the newly diagnosed phase.
- Hospices are in compliance with the PIC:TFK Implementation Guidelines in most but not all areas.
- Four of the seven hospices self-report offering all approved services to PIC:TFK enrollees; whereas three do not.

RECOMMENDATIONS

The Institute for Child Health Policy is making several recommendations for the PIC:TFK program. It is important to note that this is a complex and novel program in its second year of operation. Much has been accomplished as evidenced by the establishment of seven pilot sites with multiple program partners (CMSN Area Offices, Medical Directors, the provider community, and the families) and parental reports of positive experiences with the program. However, due to the newness and the complexity of the program, there are several areas for improvement. The recommendations made should be viewed in the context that this is a new and novel program that is in its early phases of development.

1) INCREASING ENROLLMENT

Even with the successful growth of the program, approximately 70% of the enrollment slots are unused. Identifying children for the program is complex because CMSN nurse care coordinators have large caseloads and enrollment for PIC:TFK must be considered on a case by case basis. In addition,

At A Glance

86% of parents are very satisfied to satisfied with the PIC:TFK program benefits

100% of parents of disenrolled children were very satisfied to satisfied with the PIC:TFK program

the CMSN nurse care coordinators have different perspectives about when palliative care is necessary. We have the following recommendations to increase enrollment:

- **Administrative data** can be used as one tool to identify children for enrollment. When nurse care coordinators assume complete responsibility for identifying and enrolling children into the program, they may influence enrollment, depending on their perceptions about palliative care. To reduce bias; we recommend that the Institute query the Medicaid database for children with life-limiting conditions and provide a list of children to the PIC:TFK Program Director. The Program Director can distribute these lists to the CMSN offices, which are then responsible for following up with the clients. We further recommend that we obtain feedback from each site about which children on the list were enrolled and the reasons why children were or were not enrolled. This information can be used to monitor the quality of the identification and enrollment process and to develop educational programs for the nurses and other providers as needed.
- **Technical assistance calls** and on site training should continue. Since turnover in CMSN nursing personnel can be significant, it is important to provide ongoing education and support about the program's purpose, goals, and procedures.
- **A screening tool for PIC:TFK** should be implemented at the point of initial application for

KidCare. Currently, Medicaid applicants answer questions about their child's health status using a variation of the Children with Special Health Care Needs Screener and are referred to the CMSN program based on the responses to the Screener. If the staff member believes that the child might also be eligible for PIC:TFK a flag is placed in the child's application. However, there is no structured screening tool for identifying children for PIC:TFK. The State should consider the development of a more structured tool that might allow more children to be identified at the time they apply to the KidCare Program.

- The State should be cautious about expanding the PIC:TFK program until procedures are better developed and implemented at the current sites.

2) STANDARDIZING SERVICES AND PROCEDURES

We have the following recommendations to standardize services and procedures:

- All hospices report that their staffing levels are adequate to serve the current level of PIC:TFK enrollees and that they have strategies in place to ensure appropriate caseloads. However, some of these strategies are informal assessments. As part of the continuing internal review process, the PIC:TFK Program Director should continue to **monitor staffing levels** to ensure hospices are able to manage an increased enrollment volume, while providing all needed services. In addition,

At a Glance

Administrative data should be used to identify children for potential enrollment.

A structured screening tool should be developed and implemented

Hospice staffing levels should be monitored

hospices should have formal procedures in place to assess staff levels as opposed to relying on informal reviews.

- Hospices are actively **engaging with their partners** in care, CMSN. However some hospices feel that the CMSN staff needs to take a more active role in case management and in referring children for possible program enrollment. Interviews were not conducted with CMSN nurse coordinators so their perspectives about their relationships with the

At A Glance

PIC:TFK forms should be standardized

Underutilized services should be investigated

CMSN should continue billing audits in 2007

hospice staff are not included. During the next evaluation year, interviews should be conducted with the CMSN nurse coordinators about their experiences with the program.

- The PIC:TFK Program Director should **share best practice information** to staff and provide ongoing training about operational issues.
- PIC:TFK Program **forms should be standardized** to encourage adherence to best practices across the sites. These forms could be modeled on forms currently used at exemplary

sites. For instance, one hospice has created their own forms which show how to develop a care plan, when the care plan should be reviewed, and who attended the care plan meetings.

- As the program continues to grow, all hospices should formally include the PIC:TFK Program into their existing **quality assurance protocols**. We recommend that hospices incorporate routine audit schedules for PIC:TFK into their quality programs and formally document all quality assurance activities.
- Some hospices are not offering all available PIC:TFK services to their patients. These findings raise questions about whether staffing levels are adequate to meet the children's needs and to **provide the full scope of services** that are a key part of the program concept. The PIC:TFK Program Director or the Institute should discuss barriers and capacity building activities with hospices not currently offering all services.
- Some available services are underutilized. The PIC:TFK Program Director should examine why the utilization of pain and symptom control services is low. Pain and symptom control is often overlooked in pediatric populations; yet is critical for this population of children. In addition, the Institute is examining the Medicaid claims records for the PIC:TFK enrollees to ascertain if the children are receiving these services at locations other than the hospices.
- All the hospices have a grievance policy and compliance officers. It is currently unknown how and when this information is communicated to the PIC:TFK enrollees and this will be investigated further. All hospices' should have **grievance notification procedures that include giving written information to families**.
- There were problems with billing during the first few months of operation. Although provider and services codes were specially created for the PIC:TFK Program, some hospices initially had problems implementing a billing system and receiving reimbursement. This situation has improved, and the PIC:TFK Program Director is commended for working with the sites to ensure that they understand how to bill and that they are receiving payment. When billing errors were found, the PIC:TFK Program Director took immediate action to rectify the problem.
- However, improvement is still needed in the billing procedures. We recommend that the PIC:TFK Program Director continue to formally **audit all sites in 2007** and where applicable, communicate audit findings to the other sites to prevent any future oversights or billing problems.
- We recommend that all hospices **use formal billing and audit procedures** and address any staff turnover issues that may impact performance.

3) ADDRESSING PARENT AND CHILD NEEDS

We have the following recommendations:

- The PIC:TFK sites **should perform quarterly updates**, at a minimum, on their enrollment files. The enrollment files used for the survey were out of date; several children on the active enrollment list were deceased or discharged from the program. Given that the hospice personnel work with these families on a more frequent basis, we recommend that the CMSN and hospice personnel work together to keep the CMSN records up to date.
- The State should adopt a **web-based enrollment file** or create a data entry screen in the Child Assessment and Plan System (CAPS) computer system to easily access and update the enrollment files.
- When families receive a copy of their care plans, a statement informing them that they may be contacted to **participate in an evaluation** of the PIC:TFK program should be included. This may help to improve response rates.
- Thirty-nine percent of PIC:TFK parents expressed an unmet need such as: massage therapy, music therapy (hospice was not providing this service), diapers, pet therapy, and more services for siblings. Volunteer services that include pet therapy should be considered. In addition, the **services rendered to siblings** should be reviewed to ensure that currently covered services are provided to this important group.
- The PIC:TFK children primarily received support counseling (55%) and nursing care (52%), while the families received support counseling (55%) and in home respite (16%). PIC:TFK sites should be reminded of the breadth of services offered and encouraged to offer as many services as needed and that are in accordance with the Program model. Furthermore, we recommend a **bi-annual review of the services utilized** and an **annual review of parents' reports of unmet needs** to assist CMSN in assessing the program design and benefits.
- Over 50% of the PIC:TFK families learned about the program from their nurse care coordinator. While the role of the CMSN nurse coordinator in identifying potential enrollees is a key part of the program design, we recommended that the nurses also work with other agencies and local pediatric providers to identify children.
- To ensure that all ethnic and racial groups are reached, we recommend that all PIC:TFK materials are available in Spanish and Creole and that each site has a designated contact for families who do not speak English. Furthermore, sites should be encouraged to increase enrollment of minority populations in their area by using **outreach strategies that are most beneficial for minority families**. We further recommend that the Institute contact families who refused to participate to identify potential barriers or concerns that these families have to program participation.

2 Background & Purpose

At a Glance

PIC:TFK is the first publicly-financed pediatric palliative care program in the U.S.

Children must be clinically and financially eligible for PIC:TFK to be enrolled

PIC:TFK operates in Ft. Myers, Pensacola, Gainesville, St. Petersburg, Miami, West Palm Beach, and Jacksonville

In July 2005, Florida's Partners in Care: Together for Kids (PIC:TFK) program for children with life-limiting illnesses began¹. Due to advances in technology and early screening, children with life-limiting illnesses are living longer and often do not receive comprehensive health care to meet their physical and emotional needs. Prior to the establishment of the PIC:TFK program, children with life-limiting illnesses received hospice care under the Medicare model. Designed for the elderly, the Medicare model of hospice care requires a patient to be in the last six months of life to receive hospice services and the patient must forego any curative treatments. 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:TFK is the first publicly-financed health program for children in the nation to utilize a pediatric palliative care model which integrates palliative with curative or life-prolonging therapies. PIC:TFK 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"².

PIC:TFK is operated under the authority of the Children's Medical Services Network (CMSN). The CMSN is Florida's Title V program for Children with Special Health

Care Needs (CSHCN). Children must be clinically and financially eligible in CMSN to enroll in PIC:TFK. A further clinical eligibility requirement for PIC:TFK mandates that a child is diagnosed with a potentially life-limiting illness. Children must also meet the CMSN financial eligibility requirements associated with Title XIX Medicaid (for children under 21) or Title XXI Florida KidCare (for children under 19). The enrollment of Safety-Net eligible children (who have higher incomes than Title XIX or Title XXI) in PIC:TFK is optional and based on funding availability. Finally, children enrolled in the program must represent all stages of illness: 1) newly diagnosed with a life-limiting illness, 2) mid-stage of their illness, which means that active treatment with life-prolonging or potentially curative treatments is provided, 3) end-stage where treatment options have failed. The goal is to have children approximately, equally distributed across these illness stages at each pilot site.

Formally, PIC:TFK is a pilot program operating in seven sites across the state: Pensacola, Jacksonville, St. Petersburg, Gainesville, Ft. Myers, West Palm Beach, and Miami. A child must reside in one of the seven sites and each site has an associated local hospice that has demonstrated expertise in caring for children. Participating local hospice organizations are: Covenant Hospice, Community Hospice of Northeast Florida, Hospice of the Florida Suncoast, Haven Hospice, Hope Hospice, Hospice of Palm Beach County, and Catholic Hospice.

CMSN nurse care coordinators are charged with identifying children that might be potentially eligible for PIC:TFK. The primary care physician for a potentially eligible child is contacted for a referral, and if given, the family is then approached by the CMSN nurse care coordinator about enrollment. Once a family agrees to enroll, CMSN and hospice staff collaboratively develops a plan of care for each child in PIC:TFK.

After a plan of care is agreed upon, the hospice provides palliative care services as available and deemed necessary including:

- art, music, and play therapies,
- pain and symptom control,
- in home nursing,
- in home personal care,
- respite care,
- counseling, and
- bereavement counseling.

The federal Centers for Medicare and Medicaid Services (CMS) approved the PIC:TFK program as a 1915(b) Medicaid waiver program in 2005. As a result, the State was charged under federal guidelines with conducting an Independent Assessment (IA) of the PIC:TFK program. The Institute for Child Health Policy at the University of Florida (the Institute) was awarded the IA contract and in preparation for meeting the federal assessment requirements, developed and tested survey instruments to capture family satisfaction within the program in 2005-2006. During the 2006-2007 contract year, the Institute conducted the first evaluation of the PIC:TFK program.

The purposes of this report are to:

- Describe the characteristics of children enrolled in the program from July 2006 to January 2007,
- Describe the results from a hospice administrator survey,
- Describe the State's findings from its quality assessment monitoring,
- Describe the results from the parent satisfaction and quality of health care survey,
- Describe the results from the child quality of health care survey, and
- Describe the process used to identify and the survey findings for the comparison children enrolled in CMSN.

At A Glance

**CMSN
nurse care
coordinators
identify children
for potential
enrollment from
their caseloads**



**The child's
primary care
physician (PCP)
is contacted for
a referral**



**Once the
PCP and the
family agree to
enroll, hospice
makes an initial
assessment and
develops a care
plan for each
child**

3 Data Collection & Evaluation Methods

Three data sources are used in this report. First, each PIC:TFK site submitted monthly enrollment data throughout the 2006-2007 contract period. Second, a hospice survey was sent out and responses were collected by email about operational practices, standards of care, and procedures. Finally, survey data were collected via telephone and in-homes. Survey data were collected for parents, children, and parents whose children died or were disenrolled from the program.

During the 2005-2006 contract period, a committee of University of Florida clinicians, Institute faculty and staff, and the PIC:TFK Program Director identified and selected parent and child survey instruments for use in this evaluation. The committee recommended pilot testing specific sections of several nationally recognized survey instruments for children and parents. After two rounds of testing and refinement, the parent survey was comprised of the following modules; 1) the Consumer Assessment of Health Plans Survey (CAHPS) Version 3.0, child⁴, Medicaid, 2) Pediatric Quality of Life (PedsQL), Pediatric Pain Questionnaire⁵, 3) PedsQL, Multidimensional Fatigue Scale⁶, 4) Impact on the Family Scale⁷, 5) PedsQL Core⁸, 6) selected items from Pediatric Palliative Care Project⁹, and 7) Demographics. Child surveys were comprised of the following modules; 1) PedsQL, Pediatric Pain Questionnaire, 2) PedsQL, Multidimensional Fatigue Scale, and 3) PedsQL Core.

In 2006-2007, some revisions were made to the parent surveys to meet federal reporting requirements. The revisions include: an expanded CAHPS

section, additional PIC:TFK satisfaction questions, and the Center for Epidemiologic Studies Depression Scale (CES-D)¹⁰.

The 2006-2007 parent survey contains the following modules.

CAHPS:

The Consumer Assessment of Health Plans Survey (CAHPS), child Medicaid version 3.0 was used to assess several components of the parents' health care experiences with their children. Independent Assessment (IA) instructions from the federal Centers for Medicare and Medicaid recommend using the CAHPS modules to capture program satisfaction and quality. The CAHPS questions related to the following areas:

- Ability of doctor to explain things in a useful way to parent and child,
- Choices offered to parent and child when decisions were made,
- Involvement of parent in decision making process,
- Satisfaction with care coordination, and
- Assessment of family-centered care.

The items on the CAHPS can be grouped to obtain composite scores for several domains of care including: getting needed care, getting needed care quickly, doctor communication, medical office staff, the health plan, prescription medication, specialized services, family-centered care (having a personal doctor or nurse, shared decision-making, and getting needed information), and care coordination. Initially, the

At A Glance

The parent survey included the following standardized survey modules:

CAHPS

PEDS QL- PAIN

PEDS QL- FATIGUE

PEDS QL- CORE

IMPACT ON FAMILY

CED-S

CAHPS in its entirety was tested with a sample of 10 families whose children have life-limiting illnesses. However, the items in

several of the domains focus on preventive and routine acute care needs and were not applicable to this evaluation. The domains of family-centered care (and its sub-domains), care coordination, and doctor communication were selected because these domains address critical issues for families whose children have life-limiting illnesses. The total score ranges from 0 to 100 with higher scores indicating more positive experiences with care for the composite.

PEDSQL- PEDIATRIC PAIN QUESTIONNAIRE:

Parents were asked about the amount of pain that their children had at the present time and within the past week. Parents were also asked to describe that pain and to give specific body parts where the pain had occurred. A scale of 0-10 was developed to score the responses, with 10 indicating that the child is in extreme pain. The PedsQL and the remaining survey modules are not specifically mentioned by the federal CMS. However, no IA guidelines exist for a pediatric palliative care program. The inclusion of these modules was based on a literature review about critical issues to assess for children with life-limiting illnesses.

PEDSQL- MULTIDIMENSIONAL FATIGUE SCALE:

This instrument assesses the fatigue of the child ages 2 to 18 in the past month on three levels: general fatigue, sleep/rest fatigue, and cognitive fatigue. For example, parents were asked, "Have you had any problems in

the past month with your child feeling too tired to spend time with friends?" Parents responded on a five point scale with 0 indicating this was never a problem and 5 indicating it was almost always a problem. Items are reverse scored and linearly transformed on a 0 to 100 scale. The total score is comprised of the sum of the items over the number of items answered on all scales. Lower scores indicate poorer functioning related to fatigue.

IMPACT ON FAMILY SCALE:

This instrument assesses the degree to which the child's illness has affected the following components: personal relationships, finances and other needs. The Impact on Family Scale has been shown to be applicable across diagnosis groups, socioeconomic status, family type and residence¹¹. Parents respond by strongly disagreeing, disagreeing, agreeing, or strongly agreeing to a series of 24 statements about living with an ill child. For example, parents were read the statement, "My child's illness is causing financial problems for the family." Responses are scored from 1 to 4, with five items related to coping reverse scored. The total score comprises the sum of the items, with a possible score range of 24-96. Higher scores indicate a greater impact on the family.

The items on the Impact on Family Scale can be grouped into composites that combine the responses of similarly themed questions. The composites include: financial impact (score range 4-16), familial burden (score

range 9-36), personal strain (score range 6-24) and, coping (score range 5-20). An additional six questions are asked if siblings are in the home to create a sibling impact composite (score range 6-24).

PEDSQL-GENERIC CORE:

The PedsQL Generic Version 4.0 was used to measure health related quality of life (HRQOL) in children ages 2 to 18. Parent and child versions were used where appropriate. The PedsQL Generic Form consists of 23 items associated with the following domains: physical, emotional, social, and school functioning. Each set of functioning questions is tailored to the child's age and respondents are asked to answer if their child Never, Almost Never, Sometimes, Often, or Almost Always had a problem with that functioning element. A child version was administered to children eight years and older. The items are reverse scored and linearly transformed on a 0 to 100 scale. Higher scores indicate better HRQOL.

PEDIATRIC PALLIATIVE CARE PROJECT (CHPMC) MODEL:

Questions in this module are designed for families with children in the final stages of illness. Parents are asked questions that focus on overall satisfaction, quality of information, quality of communication, quality of care, and pain and symptom management. Respondents can choose from 5 answers, with higher scores indicating higher levels of satisfaction.

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION (CES-D) SCALE:

This survey module measures parents' emotional and mental functioning. Since a child's life-limiting illness may affect the parent's ability to cope emotionally and mentally, parents were asked a series of questions that focused on how they were feeling in the past week. Respondents can choose from four answers including: Rarely or None of the time, Some or a Little of the time, Occasionally or a Moderate amount of time, and Most of the time. Responses were scored from 0 to 3 and summed, with four items related to positive feelings reverse scored. A score greater or equal to 16 is indicative of probable current depressive symptoms, with higher scores signifying greater depressive symptoms.

PIC:TFK SATISFACTION QUESTIONS:

Finally, parents were asked about their enrollment and overall experiences with the PIC:TFK program. Several questions were asked about their satisfaction with the benefits, unmet needs, and the best and worst aspects of the program.

This 2006-2007 parent survey was also administered to parents of children who had died or were disenrolled from the program, with some modifications. For

children who disenrolled, the timeframe for two modules (CAHPS, Pediatric Palliative Care Project) was adjusted to reflect the time immediately preceding the time of exit from the program. For children who died, the parent survey was limited to the following modules: 1) CAHPS, 2) Pediatric Palliative Care Project, and 3) Demographics.

In addition, a comparison group of children was identified and their parents surveyed to provide a benchmark for interpreting the PIC:TFK results. All of the children in the comparison group were enrolled in CMSN and had similar diagnoses as the PIC:TFK children; however, they reside in areas that do not offer a PIC:TFK program. Details on the comparison group are provided in the Parent Surveys of Comparison Children section of this report.

At A Glance

Parents were asked about:

- Satisfaction with PIC:TFK program benefits
- Unmet needs
- Best aspects of PIC:TFK
- Worst aspects of PIC:TFK

Parents whose children had died or disenrolled from the program were also surveyed

4 Enrollment Trends

In November 2005, the PIC:TFK Director developed a data transmission procedure for all PIC:TFK sites. Each site was required to send enrollment data at the beginning of the month using the approved template. The data file contained information on: child's name, age, contact information, stage of illness (newly diagnosed, mid stage, end of life stage), funding source (Title XIX, Title XXI, or Safety-Net), gender, admission date, discharge date, reason for discharge (if death, then death date is given), and primary and secondary diagnoses. Diagnoses are given using four digit International Classification of Diseases, 9th Revision codes (ICD-9). A separate spreadsheet reports similar information for children who were potentially eligible for PIC:TFK but not enrolled. Information on the 2005-2006 enrollment trends can be found in the Institute's report entitled, "Children's Medical Services Network: Partners in Care Together for Kids Report, Contract Year 2005-2006."

At the beginning of the 2006-2007 fiscal year, 166 children were enrolled in PIC:TFK. The percentages of enrollees by site in July 2006 were:

- Pensacola 15%
- Gainesville 5%
- Jacksonville 6%
- St. Petersburg 40%
- West Palm Beach 11%
- Miami 5%, and
- Ft. Myers 17%.

The majority of children were in mid-stage (79%), while 7% were newly diagnosed and 13% were end-stage. Children were ranked by diagnoses and the top 10 were: Congenital Anomaly/Genetic, Brain Injury/Development, Leukemia, Muscular Dystrophy, Cerebral Palsy, Cystic Fibrosis, Convulsions, Cardiovascular Disorders, Transplants, and HIV. Ninety-four percent were Title XIX eligible, 5% Title XXI, and 2% eligible through Safety-Net.

By January 2007, which was the most recent enrollment data file received from CMSN, the PIC:TFK program had grown 51%, to 251 children. The percentages of enrollees by site in January 2007 were:

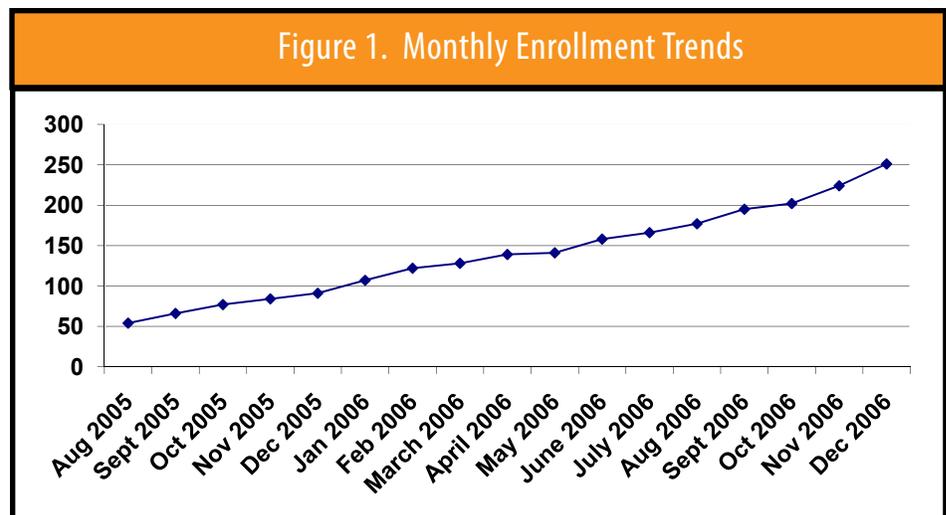
- Pensacola 16%
- Gainesville 8%
- Jacksonville 9%
- St. Petersburg 33%
- West Palm Beach 14%
- Miami 4%, and
- Ft. Myers 16%.

In January, the majority of children were still in mid-stage (80%), while 10% were newly diagnosed and 10% were end-stage. Children were ranked by diagnoses and the top 10 were: Brain injury/development, Congenital Anomaly/Genetic, Muscular Dystrophy, HIV, Cerebral Palsy, Leukemia, Cystic Fibrosis, Leukodystrophy, Cardiovascular Disorders, and Convulsions. Ninety-one percent were Title XIX eligible, 7% Title XXI, and 2% Safety-Net.

Figure 1 shows that monthly enrollment in PIC:TFK has steadily increased since implementation and exceeded 200 for the first time in October 2006.

By site, enrollment has grown from July 2006 to January 2007 by:

- 60% Pensacola,
- 162% Gainesville,
- 130% Jacksonville,
- 90% West Palm Beach,
- 22% Miami,
- 41% Ft. Myers, and
- 19% St. Petersburg.



5 Survey of Hospices

At A Glance

Six of the seven hospices have operated in Florida for more than 22 years

All of the hospices are not-for-profit entities

Hospice staff has little to no staff turnover

In November 2006, the seven participating hospices were emailed an administrator survey about their operational practices, standards of care and procedures. This survey was adapted from the Managed Care Organization (MCO) Administrator Guide developed at the Institute. The MCO Administrator Guide has been reported in published papers^{12, 13}. This survey was emailed to both the

program's primary hospice contact and to the hospice CEO. The survey covered the following areas:

- Organizational structure
- Care plans and care coordination
- Quality assessment and performance improvement
- Service utilization
- Enrollee rights and grievance procedures
- Health information systems and billing procedures
- Best and worst aspects of the program

Survey questions assessed the hospices' compliance with the PIC:TFK Implementation Guidelines and their performance against standard organizational measures. In some cases, hospices were asked to provide their local policy documents and forms as supporting evidence. Survey findings provide valuable baseline information against which the success of the program can be measured in the future.

All seven hospices responded to the survey. Results of the hospice administrator survey are presented below by section:

ORGANIZATIONAL STRUCTURE

There are 41 registered hospices operating in Florida, of which seven hospices currently participate in the PIC:TFK program. Nationally, only 18% of hospice programs surveyed by the National Hospice and Palliative Care Organization are able to actively provide a pediatric palliative care program¹⁴, and 14% percent report that they never admit pediatric patients¹⁵.

The organizational structure of the participating hospices is very similar. Six of the hospices have operated in Florida for more than 22 years, with an average length of operation of 23.7 years (standard deviation 7.3 years). These six hospices serve an average of 2,376 patients (standard deviation 1,166) per month, following the trend for Florida's hospices to be six times larger than the rest of the nation¹⁶. One participating hospice has been in operation for eight years and serves comparatively fewer patients a month (280 patients).

All the hospices are not-for-profit organizations and are not publicly traded. This is in contrast to national figures showing that 27% of hospices report 'for-profit' status¹⁷. All hospices offer a program for children regardless of their type of insurance, family income or ability to pay. During their last measurement month, either October or November 2006, all but one hospice reported providing care to children not enrolled in the PIC:TFK program. However, the number of pediatric patients outside of the PIC:TFK program is very small, accounting for only 0.1% to 4.7% of the population served by each participating hospice that month.

There is stability among staff within the PIC:TFK program. In the last year, there was no staff turnover of registered nurses, licensed practice nurses, or social workers/therapists involved with the PIC:TFK program at six of the seven sites. The turnover that did occur was due to staff moving out of the area. Furthermore, there was limited staff turnover in the hospice overall, with less than 18% reported turnover in registered nurses during

each of the last three calendar years. Program stability was also reflected in hospice management and leadership. Five of the seven hospices had the same Medical Director since the program's implementation, and these Medical Directors had between three and twelve years experience at that hospice.

All hospices used strategies to assess staffing levels for the PIC:TFK enrollees. These strategies involved informal review of enrollment numbers, service use, and staffing ratios to determine if more staff was needed. At two hospices, the administrators reported that the number of PIC:TFK enrollees are so low that staffing has not been an issue. Only one hospice has guidelines for staffing levels of children that specifies the pediatric caseload.

Under state regulations, hospices must have someone on staff 24 hours a day, seven days a week available to patients. All hospices offered this support service to PIC:TFK enrollees, in adherence with the PIC:TFK Implementation Guidelines. PIC:TFK enrollees were given an after hours number which is staffed at all times.

Six hospices indicated that they provide services for participants who are hearing impaired or who have limited English proficiency. One hospice did not comment on whether these services were available, only that they "have not had to address this at this time." Four hospices utilize relay or TTY technology for the hearing impaired, or work with other agencies to provide these services.

CARE PLANS & CARE COORDINATION

All hospices were compliant in developing a written care plan for the children. As one hospice reports, "the hospice model is based on care planning, with the patient in the middle of care, directing the plan of care. We follow the same process for our PIC:TFK clients [as our other pediatric patients]." The PIC:TFK care plan is developed in consultation with the families, taking into account their needs. Families can receive services as quickly as 2 days and no more than 2 weeks post assessment unless the family expressly requests a different time frame. Four hospices commented that any delays in scheduling a visit are at the families' requests and not because the staff are unavailable. Hospices reported officially revising the care plan every 3 months to every year, although six hospices noted that they revise the care plan more regularly based on the changing needs of the patient and the family. All hospices monitor staff and patient adherence to the care plans and all but one hospice keep records of adherence. All hospices report that families are receiving timely access to care and services.

One of the core elements of the PIC:TFK program is that hospices actively engage with patients and their partners in care, CMSN. There was ongoing communication between the hospice and CMSN and formal team meetings to discuss the child's care coordination activities. Each hospice has a designated PIC:TFK program coordinator, which is either a nurse or a social worker/social service counselor. These program coordinators have the primary

At a Glance

One hospice reports:

"The hospice model is based on care planning, with the patient in the middle of care, directing the plan of care. We follow the same process for our PIC:TFK clients [as our other pediatric patients]."

All hospices hold at least monthly meetings with their CMSN partners

responsibility of coordinating the child's care with CMSN. All hospices report holding monthly team meetings with CMSN staff to conduct an interdisciplinary review of the children's care plans. Four of the hospices held these monthly joint case conferences in person however one hospice held quarterly

face to face meetings with monthly teleconference calls in the interim. Two hospices did not report whether monthly meetings were done in person or on the phone.

All hospice staff reported communicating with staff at the CMSN area offices regularly about the progress and experiences of each PIC:TFK child and whether the plan of care may need to be

revised. Contact was made as soon as possible if there were newly identified needs or concerns. Communication was primarily by telephone, but also by email or face to face when appropriate.

Five hospices commented that children in the PIC:TFK program were different from their other pediatric patients, in terms of severity of illness or that many were not yet requiring end-of-life care. This difference in patient populations is consistent with the goal of the PIC:TFK program, which is to integrate curative and palliative care throughout the course of the life-limiting condition. Hospices felt confident in helping patients transition from one stage of illness to the next. During transitions from one illness phase to another, hospice staff indicated that they would discuss all options with the family and CMSN staff and incorporate any new services into the existing care plan. One hospice reported this may mean:

“Bringing on other team members (e.g., chaplains, music therapists) or coordinating services with CMSN or other community organizations to give families more medical information they need. It can also include information (e.g., flyers, booklets) on specific topics such as end of life or pain management.”

Hospices recognize that some PIC:TFK children will have a longer lifespan than children in traditional hospice care. If a PIC:TFK enrollee lives beyond 21 years, hospices were asked if they had any specific approaches in place to address transition to adulthood. Two hospices mentioned that they had adult palliative programs available to these patients. Where the transitioning child was not eligible

for full hospice care and no adult program was available, hospices reported that they would review cases on an individual basis, assist families in connecting with other community resources; while offering social service, spiritual and nursing interventions during the transition period.

Under the PIC:TFK program, children have contact with the hospice system earlier than they would have otherwise. It is important for each hospice to keep the child’s primary care provider (PCP) abreast of services provided. Two hospices had structured contact with the child’s PCP on a monthly basis. One of these two hospices communicated with the child’s PCP monthly via written updates from the electronic medical record, which contains information from the care plan meeting and any visits to the child. The other five hospices reported communicating with the child’s PCP in an ad-hoc manner, the frequency depending on each child’s needs.

Hospices are conducting outreach to physicians in the community and other agencies about the PIC:TFK program. Hospice nurses, community educators, or professional relations staff discuss the PIC:TFK program during regular physician outreach visits. One hospice always “discusses PIC:TFK as part of our continuum of care when providing information about our program/hospice in general.” Hospices reported using different educational forums including: workshops, lunches, seminars, brochure mail outs, Grand Rounds, and hospital newsletters. The amount and intensity of these activities varies between hospices and their existing capacity for

At a Glance

One hospice reports that transitioning across illness stages might mean:

“Bringing on other team members (e.g. chaplains, music therapists) or coordinating services with CMSN or other community organizations to give families more medical information they need. It can also include information (e.g. flyers, booklets) on specific topics such as end of life or pain management.”

sophisticated marketing and public relations. One hospice reported that they include the PIC:TFK program in all their internal publications and website.

QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT

Quality assurance activities are an important activity within any organization to identify best practices and areas where improvement is needed. All hospices had a quality program with designated staff, and three hospices used quality of care measures for children in the PIC:TFK Program. The three hospices with a dedicated PIC:TFK Program assessment completed audits monthly to quarterly. In addition, the Quality Directors and committee members at these hospices reviewed and updated their performance improvement plans annually and reviewed their quality assessment findings at monthly meetings. One hospice measured racial disparities within its patient population.

Four hospices have not formally incorporated the PIC:TFK Program into their existing quality programs. Quality monitoring occurs on an ad-hoc or informal basis. All hospices reported the capacity to regularly monitor compliance with PIC:TFK standards for timely access to care and services, whether this was by weekly review of provided services or an ad hoc review of charts. No hospices used financial incentives or penalties to encourage compliance with quality assurance reporting requirements.

Some hospices felt that their census of children was currently too low to implement a formal quality assessment and performance

improvement plan. One hospice reported that they were waiting until after the first year of operation and the Program Director's site visit to formally implement a quality program for PIC:TFK. Only one hospice distributed a staff satisfaction survey to its staff, but this survey was not specific to the PIC:TFK program.

Four hospices volunteered that their PIC:TFK staff is closely supervised and case reviews are conducted to ensure they are following the PIC:TFK Implementation Guidelines. Hospices reported the following staff training activities: preceptorships, educational seminars, standard orientation sessions, and formal pediatric training courses. As part of the new staff orientation, hospices report that they educate staff members about enrollees' rights, privacy and confidentiality issues and HIPAA responsibilities. Some hospices also provide regular updates to their staff members about the PIC:TFK program about new policies or procedures, customer service issues and other information of interest. PIC:TFK information was communicated by a variety of methods, from email updates to staff meetings, and internal publications.

SERVICE UTILIZATION

Under the PIC:TFK Implementation Guidelines, hospices are reimbursed for the following services: counseling, in home nursing care, activity therapies, inpatient respite, in home respite, in home personal care and physician consultations for pain and symptom control. Currently, not all hospices have the capacity to provide all

of these reimbursable services to PIC:TFK enrollees. Four of the seven hospices offered all services to families while three hospices offered reduced services.

Three hospices were not able to provide all services to PIC:TFK enrollees. Inpatient respite and personal care were not available at

At A Glance

All hospices have a quality improvement program, but are encouraged to incorporate specific measures for PIC:TFK

Hospices educate their staff about PIC:TFK through training, meetings, and newsletters

Four hospices offer all the PIC:TFK services

5. | Survey of Hospices

one hospice while another hospice currently did not provide activity therapy because they were in the process of hiring a new registered activity therapist. This hospice however indicated that their support counselors employ therapeutic art and play techniques during their counseling sessions. One hospice did not offer activity therapy, respite (inpatient or at home), or physician consultations for pain and symptom management.

Hospices were asked to self-report the PIC:TFK services for which they claimed reimbursement between August 2005 and August 2006. During this time period, hospices claimed (in descending order of frequency): support counseling for children and parents, nursing care, and activity therapy. Support counseling was the most common service provided at four sites, accounting for 45% of all claims. However, each hospice differed in their service profile with some sites focusing mainly on activity therapy and others on nursing care. Even hospices that focused predominantly on support counseling differed in the other services they provided, some

providing respite, others personal care. The breakdown of service provision by service type at each site is given in Table 1.

During August 2005 to August 2006, two hospices reported having their claims for services denied. The billing issues are unique to those hospices and the PIC:TFK Program Director and the Agency for Health Care Administration are addressing this issues.

During August 2005 to August 2006, some PIC:TFK services were underutilized or not utilized at all. Under the PIC:TFK Implementation Guidelines, hospices may provide up to six hours of personal care per day, one pain and symptom control consultation by a physician per day, and respite of up to seven days per year. Only three claims in total were made for physician consultations. Three hospices did not make any claims for personal care services and two hospices did not claim any respite services. It is possible that these services are being rendered at other locations. The Institute is currently assessing the Medicaid claims and encounter data for the enrolled children to

determine if there are paid claims for these services delivered by providers other than the participating hospices.

Currently hospices are not reimbursed for providing volunteer or bereavement services. One of hospices' core services is to provide bereavement services to families in need. To date, three hospices have provided bereavement services to families involved with the PIC:TFK program.

All hospices offer volunteer services to PIC:TFK enrollees. Five sites actively provided volunteer services between August 2005 and August 2006, however at two sites only a few families used the volunteer services. For example, one family was the sole recipient of volunteer services (11 hours) at one hospice site and three families received a total of 30 hours of volunteer services at another hospice. Six of the seven hospices reported logging the number of volunteer hours.

Hospices also reported providing value-added services to PIC:TFK enrollees, such as holiday parties and holistic and integrative

Table 1. Self-Reported Service Profile by Hospice Sites, August 2005-2006

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7
Support counseling	74%	75%	24%	58%	36%	33%	25%
In home nursing care	3%	0%	76%	16%	60%	16%	14%
Activity therapies	0%	6%	*	0%	*	51%	61%
In home respite	22%	19%	0%	7%	*	0%	0%
Inpatient respite	0%	1%	0%	0%	*	*	0%
In home personal care	0%	0%	0%	19%	4%	*	0%
Pain/symptom consultation	1%	0%	0%	1%	*	0%	0%

* Service not available to PIC:TFK enrollees

At A Glance

No grievances were filed during the past year in the PIC:TFK program

All hospices track the provided services

Five hospices audit their PIC:TFK claims and encounter data

therapies. Additionally some staff make hospital visits, provide discharge planning, and attend doctor's appointments when requested. Hospices also link children to community programs such as Make-A-Wish Foundation, Christmas Angel Tree and support camps. Hospice staff provides information to families about financial assistance programs, food stamps, food shelters, other counseling services, housing information, crisis line, and mental health agencies.

ENROLLEE RIGHTS AND GRIEVANCE PROCEDURES

All hospices must have written grievance procedures as required by the hospice accreditation board.

No grievances were filed during the past year. However there are standard grievance procedures at each site. All hospices have a compliance officer to oversee the grievance and appeals process (Vice President (VP) of Planning, Director of Quality, VP of Corporate Compliance and Quality Improvement, VP of Organizational Excellence and Corporate Compliance, VP of Clinical Services, or Risk Manager/ Compliance Officer). Any enrollee filing a grievance can seek assistance from the compliance officer or a representative.

Two hospices volunteered information that they explicitly advertise their grievance procedures to PIC:TFK enrollees in handouts or brochures. One of these two hospices gives patients and families a specially designed Bill of Rights for PIC:TFK patients at the time of admission which explains the enrollee's rights and who to contact if they have unresolved issues, starting with the Supportive Care Director. This hospice has a written statement that informs patients that they can make a complaint without fear of restraint, interference, coercion, discrimination or reprisal and that they also have the avenue of calling the Florida Statewide toll-free telephone number to report abusive, neglectful or exploitive practices.

HEALTH INFORMATION SYSTEMS & BILLING PROCEDURES

Each hospice program reported tracking all services provided to the children and families enrolled in PIC:TFK, both reimbursed and not reimbursed. Data are tracked

in a variety of systems, including SQL Server 2000, Therapist Helper, and Progress, MiSys. All of these systems are relational databases, which allow the user to manipulate data and create queries and updates. No hospice reported using unsophisticated systems such as hierarchical or flat files. Four of the hospices indicated that their databases are proprietary, where a company designed the database to meet the needs of the hospice.

All hospices back up their systems daily and six report that they store copies of the data in an offsite secure location, with two hospices replacing the off-site copies as frequently as weekly. The hospices reporting that they replaced their off-site copies weekly volunteered this information. In future hospice administrator interviews, all hospices will be asked how frequently they replace their off-site copies.

Five hospices audit their PIC:TFK claims and encounter data. Three of the sites have policies which include a monthly audit schedule, whereas two of the hospices periodically audit their financial records. At the hospices with a monthly audit schedule, the finance department runs an accounts receivable history to reconcile any outstanding balances.

Two hospices did not report auditing their financial records at all. One hospice reported having no formal system in place. These two hospices reported numerous billing problems including: no written policies for billing and auditing, reliance on manual tracking systems as opposed to computerized systems, high staff turnover in their financial services

departments, and the lack of an editing system to track claims adjudication.

BEST AND WORST ASPECTS OF THE PIC:TFK PROGRAM

The hospices support the PIC:TFK Program mission and goals. When asked about the best aspect of the PIC:TFK Program, most cited that the program afforded children and families greater access to services not available through traditional models. For three hospices, one of the best aspect of the PIC:TFK program was the opportunity to collaborate with staff at CMSN. However some problems were reported with the collaboration. For example, three hospices reported that CMSN could benefit from more education about the program. Five hospices requested more training about operational issues for both themselves and CMSN staff. One hospice suggested employing a consultant who could assist the hospice and the local CMSN in developing the PIC:TFK Program at the local level. Some hospices felt that additional education should primarily be directed toward CMSN staff to ensure “buy-in” and understanding of the program and the role of the hospices. Hospices felt that there should be a more active and effective role for CMSN staff in management and service delivery for PIC:TFK patients.

“Increase education to insure “buy-in” and understanding of program from CMSN nurses and staff. More integration of services and delivery of those services between CMSN and the hospices. More active and effective role from CMSN partners in management and service delivery

for PIC:TFK patients. Hospices need to have a better awareness and understanding of CMSN roles and services.”

“Programs involved in the PIC:TFK program would benefit from having the roles within the PIC:TFK program more clearly defined....It would be helpful for hospice organizations to receive information on best practices for our professional staff. Although we understand this is a pilot program, it seems it has been in existence long enough to glean best practice information.”

Two hospices felt that identifying eligible children could sometimes be problematic and that CMSN staff needed to better understand the importance of making referrals to the hospice.

“More education to all involved but primarily the CMSN Support Coordinators to understand the importance of making referrals and the importance of our overall participation in the program.”

“For children who are referred while in the hospital, we believe [hospice] could provide a more seamless transition if we were allowed (and reimbursed) to participate in the hospital discharge planning process with all of the child’s care providers.”

One hospice commented that the best aspect of the PIC:TFK Program was that it promoted an increased awareness and appreciation for community-based hospice care. One hospice felt that reimbursement for activity therapies (i.e., play, music and art) is low and prohibited the hospice’s ability to attract therapists to the PIC:TFK program. Another hospice felt that the PIC:TFK program does not

have provisions for reimbursement when hospice staff visit PIC:TFK patients in the hospital, leading to a loss in continuity of care

At a Glance

“Increase education to insure “buy-in” and understanding of program from CMSN nurses and staff. More integration of services and delivery of those services between CMSN and the hospices. More active and effective role from CMSN partners in management and service delivery for PIC:TFK patients. Hospices need to have a better awareness and understanding of CMSN roles and services.”

6 Quality Assessment Monitoring

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During the fall of 2006 the PIC:TFK Program Director enacted an annual monitoring protocol that included site visits, chart reviews, and entrance and exit interviews for all the PIC:TFK participating agents. These agents include representatives from the local hospice, CMSN office, and the Agency for Health Care Administration. Representatives of each agency met to review and evaluate whether the Implementation Guidelines were being met. Patient charts from the hospice and CMSN were reviewed and the strengths and weaknesses of the program were discussed. Staff from the Institute attended these monitoring visits to observe; however, the PIC:TFK Program Director conducted the monitoring protocol. This report does not duplicate the Director's findings from the monitoring visits. A copy of the PIC:TFK Program Director's full report can be found in Appendix A.

7 Parent Surveys

As part of the IA, the Institute conducted surveys with parents and children in PIC:TFK. In total, 64 PIC:TFK parents completed the survey. Twelve of these surveys were conducted in-person for PIC:TFK Program enrollees. The CMSN area offices participating in the program provided the families' contact information. Due to a high percentage of missing and invalid numbers, the CMSN area offices were contacted in January 2007 and asked to provide updated contact information. All offices attempted to comply, but some of the contact information could not be updated. The overall response rate for this survey is 53% of those with valid contact information. Approximately 31% of the sample has missing or invalid information. Results for the parent survey are presented below by section:

DEMOGRAPHICS

Of the 64 parent respondents whose children are enrolled in the PIC:TFK program, the mean age is 41 with a standard deviation of 11.9 years. Fifty-two percent of parents are White, 20% Black, and 27% Hispanic. The PIC:TFK parents report that 44% of their children are White, 27% Black, and 28% Hispanic.

Equal numbers of PIC:TFK parents have completed high school or some college (37%), while 35% have not

graduated from high school and 27% have an Associates degree or higher. Forty-two percent are married, 40% are single, and 9% are divorced. Equal numbers live in a single and double parent household. The majority of PIC:TFK parents (78%) and verbal children (78%) speak English at home.

As seen in the chart below (**Figure 2**), 75% of PIC:TFK children are in school or daycare while 91% have a sibling. More PIC:TFK parents of males than females responded to the survey.

PIC:TFK SATISFACTION AND EXPERIENCES

This section of the survey asked specific questions about the respondents' experiences and satisfaction with the PIC:TFK program.

Parents were first asked how they learned about the PIC:TFK program and they indicated the responsible party was (respondents could choose more than one):

- Nurse care coordinator 52%,
- Provider 16%,
- Brochure 5%,
- Friend or family member 8%,
- Social service agency 6%,
- Hospital 11%,
- Internet 3%, and
- Other 23%.

At A Glance

Parent survey response rate is 55%

75% of PIC:TFK children are enrolled in school or daycare

52% of PIC:TFK parents learned about the program from their child's nurse care coordinator

Figure 2. Percentage of Children in PIC:TFK: In School or Day Care, With Siblings, & Gender

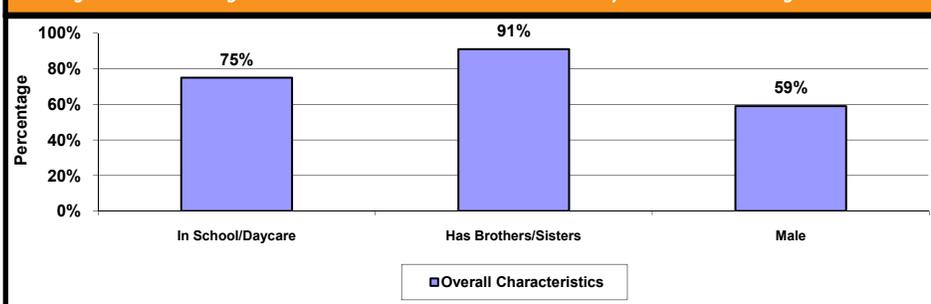


Figure 3 shows the amount of time from when the child was invited to participate in PIC:TFK to when he was enrolled, with the majority being enrolled in under 2 weeks.

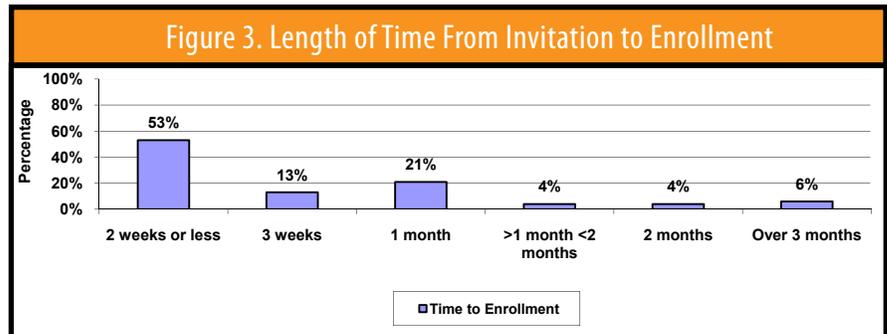
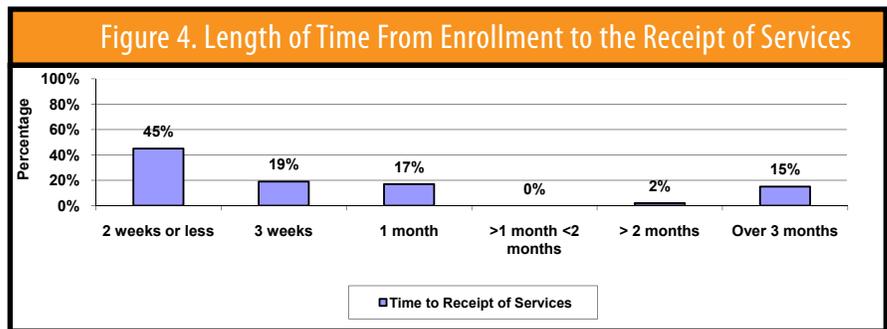


Figure 4 summarizes the families' report of the length of time from program enrollment to the receipt of services. Most children received timely services (2 weeks or less), but 15% did not receive services for at least three months.



When asked what services their child had received, parents responded¹⁸:

- Support counseling 55%,
- Music therapy 36%,
- Art therapy 13%,
- Play therapy 14%,
- Pain and symptom management 20%,
- Personal care 19%, and
- Nursing care 52%.

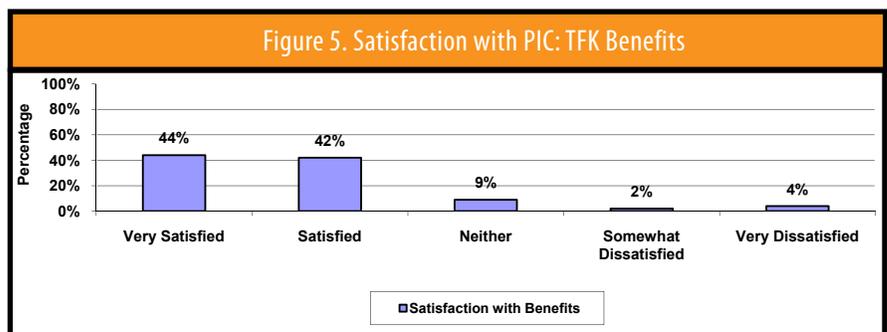
When asked what services the family members had received, parents responded:

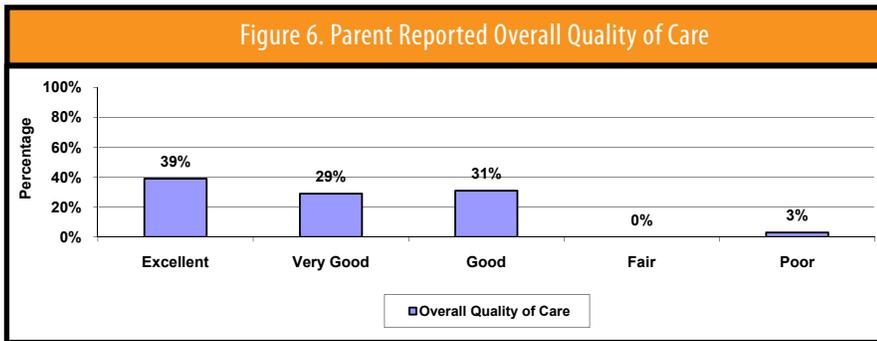
- Support counseling 55%,
- Music therapy 13%,
- Art therapy 3%,
- Play therapy 5%,
- In home respite 16%,
- Inpatient respite 6%, and
- Volunteer services 13%.

Parents were asked a series of questions about their satisfaction with the PIC:TFK program. First, parents were asked how satisfied

they were with their child's PIC:TFK nurse or therapist. Sixty-nine percent were very satisfied, 19% were satisfied, 7% were neither satisfied nor dissatisfied, and 6% were somewhat dissatisfied to very dissatisfied.

Figure 5 shows that most parents are very satisfied to satisfied (86% of PIC:TFK parents) with the program benefits.





Ninety-five percent of respondents would recommend the program to a family member or friend. Only one PIC:TFK parent has made a complaint with CMSN. When asked about the quality of care their child receives in PIC:TFK, 68% indicated that the quality is excellent or very good (**Figure 6**).

PARENT RESPONSES

Parents were asked open-ended questions about the best and worst aspects of the program and about unmet needs. When asked about the best aspects of the program, many parents said the program was family-centered, the staff was compassionate and supportive, and the therapies beneficial. Several parents commented that they would be unable to cope without the program and that it was “what kept me together and my family together.”

“The program is awesome. I’m glad it’s here. Without them we wouldn’t know what to do. It makes it easier for us to deal with what we’re going through....I think these services should be offered around the world!”

“I just can’t imagine going through this all without them. I know they

will be there for us when things get rough. They got to know us now when things are calm and I know they’ll be there for him when he’s ready to die. They’re part of the network of support now.”

Parents frequently commented that they enjoyed the level of support and the peace of mind that that brings, especially for working parents.

“Knowing that it’s there and there’s a security blanket. It’s wonderful to know the kids will be well cared for when we’re away. For most people living with this type of child, the days are weary and long - it’s good to know someone is helping and you have support.”

“Everybody is always just so friendly and considerate. Having spent time with anyone from the program I always walk away feeling better. They have a really compassionate attitude and are empathetic. It makes me feel better about myself as a parent...It alleviates some of the stresses I feel from society because my child is different...It also provides me with peace of mind that he is getting friends and is not alone while I’m at work.”

Many parents commented that they felt reassured that there was always someone they could call on for assistance and rely upon when they needed them.

“The nurses are amazing how they coordinate everything, they are very involved, very hands-on. They stepped in when we needed them.”

“The counselor and nurse call all the time. Even if I’m too busy they still call at least once a week. And if you call them, they help you right there and then. And if it’s going to take them a couple of hours to get the information or service then they’ll call back and say, I’m working on it....It’s just wonderful.”

Parents of children in the PIC:TFK program felt that the staff was knowledgeable and genuinely concerned about their child, and were there to “listen and care about my child’s progression.”

“The nurses were so helpful and concerned- nice, genuine, like they really cared.”

“The counselor knows her illnesses, she know how to work with us, she’s been trained to help and my child enjoys being with her.”

“I like the fact that the communication lines are open - everybody is communicating and informing the parents of changes... They help fill the gap for the rest of the family and things that are non-medical related. It also helps to have that person accountable for my daughter’s needs.”

The PIC:TFK program is designed to address children’s unique needs. For some parents, the best thing about the program is the activity therapy (music, art), for others it is respite, nursing or support counseling. Some parents like the variety in the PIC:TFK program, giving the child a chance to “do something else” and interact on a different level.

Several parents commented that the PIC:TFK program is a good source of information about community resources available to parents of children with special needs.

“They helped with questions about other programs.”

“They let parents keep up with what is currently available –if you don’t know what is currently available you can’t get the best for your child.”

When asked about the worst aspects of the PIC:TFK program, some parents said that the program staff needed to raise awareness about the program and “get moving in getting people into it.” Some parents also felt that the program is under-funded and that staffing issues limited the frequency of visits. This is especially apparent at one site where parents commented:

“I think the services are just too limited and the frequency of visits is too limited as well. For instance the therapist used to come around once a week and now she comes once a month. Perhaps they need to look at their staffing.”

“I’ve got nothing bad to say about the program. It’d be nice if they could come out more often, maybe try and come more than once a month...but I realize there are limited funds.”

Thirty-nine percent of the PIC:TFK parents report having unmet needs. Some of these unmet needs are respite, music therapy, art therapy, massage therapy and counseling for parents or more services for siblings. Several parents wanted tangible things such as medical

supplies and diapers. A few parents wanted reinstatement of services that had been interrupted, either because of staffing issues or a change in care coordination teams.

“I am satisfied with the services we get, but some services are not available to us and so I am not happy about that. I’d like to see respite offered to families.”

One parent commented that they received poor quality of care and would not recommend the program, because of an incident where “someone pulled the G-tube and I had to take my child to the ER.” One other parent was dissatisfied with the program because they had never received services.

“He was signed up and nothing happened. No-one else has given me any information about the program. They wasted my time and offered me nothing.”

CAHPS

Results from the CAHPS Composite Scores are described in this section. Results from the individual items for the CAHPS and all other survey sections can be found in the technical appendix that accompanies this report. Composite scoring combines the responses of similarly-themed questions. For example, individual items related to care coordination are grouped according to the developer’s instructions and scored on a scale of 0 to 100, with 100 being the highest.

CAHPS Composite Scores were calculated for: family-centered health care - personal doctor or nurse, family-centered health care - shared decision making,

At a Glance

“It’s nice when the art and music therapist come and see her - it also gives me time to myself. It’s fun for her, she enjoys it. It gives her someone who comes out just to see her- which is good for her self esteem.”

“I know they have picked up more children in the program but I don’t think they should take on more children if they can’t handle the caseload they already have.”

family-centered health care - getting needed information, care coordination, and doctor communication. PIC:TFK parents responded with an average composite score of 84 for doctor communication, 83 for family-centered care- personal doctor or nurse, 85 for family-centered care- shared decision making, 89 for family-centered care- getting needed information, and 78 for care coordination (**Figure 7**).

Although not included in the CAHPS composites, respondents were also asked to rate their overall healthcare on a scale of 0 to 10, with 10 being the highest. PIC:TFK parents gave their child's healthcare a mean score of 8.73 (standard deviation 1.65).

PEDS QL MULTIDIMENSIONAL FATIGUE ASSESSMENT

The composite scores for the PedsQL Multidimensional Fatigue Assessment Scale are presented in this section.

There are three fatigue composites: general fatigue, sleep/rest fatigue, and cognitive fatigue. **Figure 8** shows that the PIC:TFK families scored 45 for cognitive fatigue, 50 for general fatigue, and 59 for sleep/rest fatigue on a scale of 0 to 100. Lower scores indicate poorer functioning.

PEDS QL GENERIC ASSESSMENT

The composite scores for the PedsQL Generic Scale are contained in this section. The PedsQL Generic Scale has the

following domains: physical, emotional, social, and school functioning. **Figure 9** shows that the PIC:TFK children scored 32 on physical, 61 on emotional, 52 on social, and 49 on school functioning.

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION (CES-D) SCALE

Scores greater than or equal to 16 on the CES-D indicate the presence of current depressive symptoms. Of the PIC:TFK respondents, 48 scored greater than or equal to 16 (75%) and their mean score was 26.3 (standard deviation 7.5). This information can be used to document the need for supportive and counseling services for parents whose children have life-limiting illnesses. In addition, this information is important for future evaluations. Studies have shown that parents with depression tend to rate their children's HRQOL lower than parents without depression. When sufficient data is available, the parents' CES-D will be used as a control variable when assessing the impact of the program on children's HRQOL.

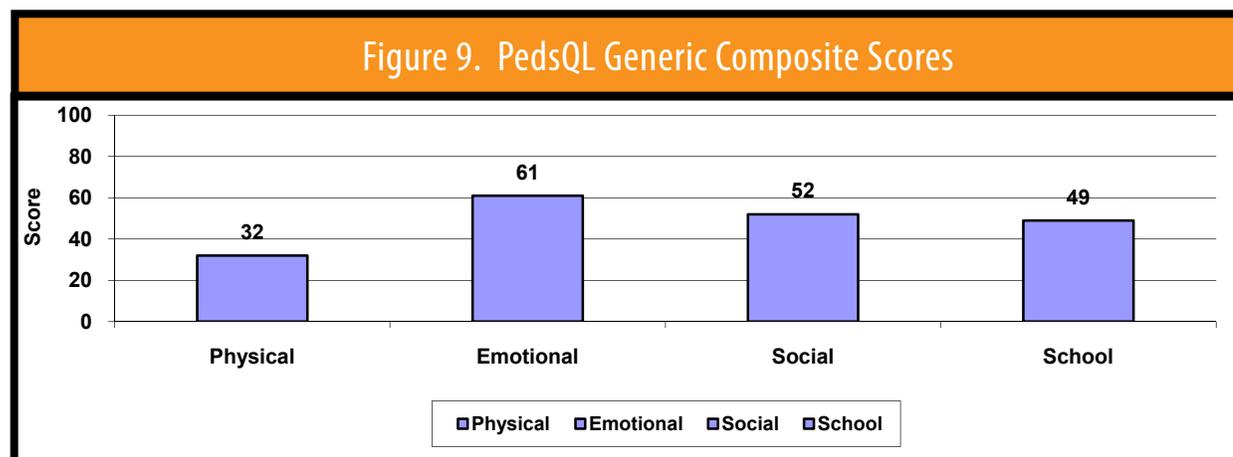
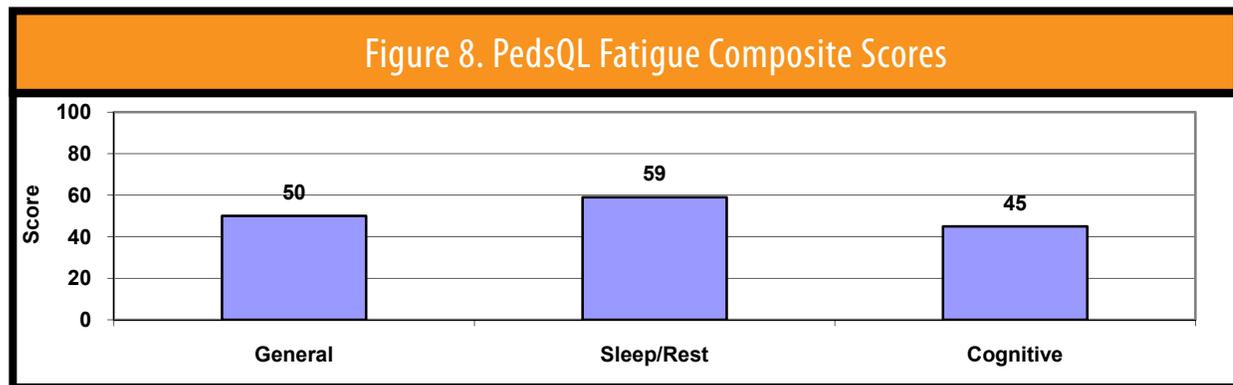
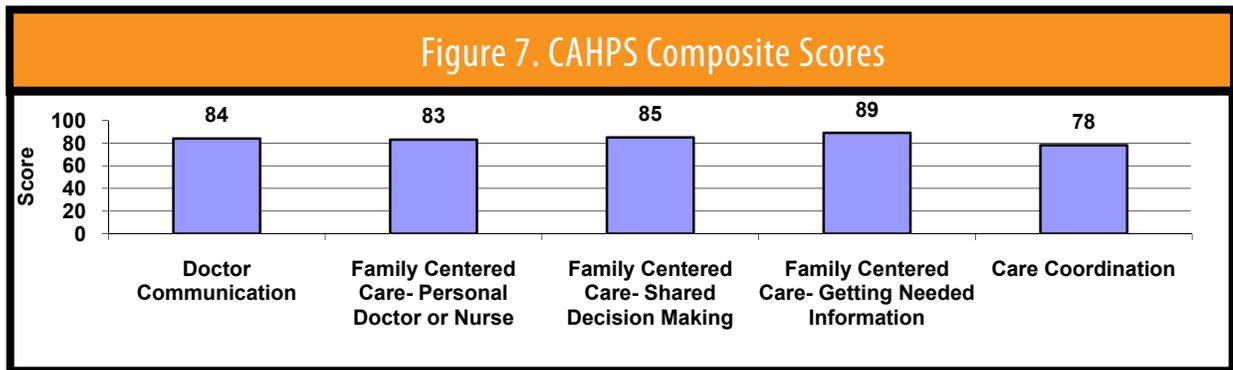
IMPACT ON FAMILY SCALE

The Impact on Family Scale was developed to measure the impact of a child's illness on the family. A higher total score on the Impact on Family Scale is indicative of larger effects. Parents in the survey reported a total score of 63.1, which is higher than other studies of chronically ill children^{19, 20}. PIC:TFK parents responded with an average composite score of 11.8 for

financial impact, 24.8 for familial burden, 17.6 for personal strain, 9.3 for coping, and 13.7 for sibling impact. These are slightly higher than national and international studies of chronically ill children. Results from the individual items for the Impact on Family Scale can be found in the technical appendix that accompanies this report.

PEDS QL PEDIATRIC PAIN ASSESSMENT

Parents were asked how much pain their child was feeling at the time of the interview on a scale of 0 to 10 with 10 being extreme pain. PIC:TFK parents report a mean pain score of 2.1 (standard deviation 2.8). Parents were also asked how much pain their child had experienced in the past week on a scale of 0 to 10. PIC:TFK parents report a mean pain score of 2.9 (standard deviation 3.0).



8 Child Surveys

At A Glance

9 PIC:TFK children/ adolescents completed the survey

No recommendations are made due to the limited amount of data

As previously described, when possible, children in PIC:TFK were surveyed about their health-related quality of life (HRQOL). Only children eight years and older were contacted for a survey (approximately 60% of parents who completed the survey had a child meeting the criteria). Parents were first asked if they would allow their children to participate. Twenty-six of the responding parents indicated that they would not allow their children to be interviewed, 18 of whom said their children were nonverbal and five said their children did not have the cognitive skills to answer questions (three parents did not give a reason why their children could not be surveyed). Once the parent agreed, the child was contacted at another time and interviewed privately. Nine PIC:TFK children completed the survey.

Only item by item responses are presented in the technical appendix that accompanies this report because few children completed the surveys. The information gathered in the child interviews is presented only to demonstrate the HRQOL for a small number of children. As such, no overarching recommendations can be made based on so little information. However, it is important to continue collecting information from the child's perspective about his or her HRQOL. A substantial body of literature demonstrates that children and parents often differ

in their health-related reports. Understanding the parents' and the children's perspectives can enhance the quality of care provided.

Item responses in the technical appendix include responses to the PedsQL Generic Scale, the PedsQL Multidimensional Fatigue Scale, and the final section of survey questions for children. These final questions ask a variety of questions related to spirituality, participation of the child with his or her health care, and ability to talk about his health with family and friends. Only children 12 years and older were asked these questions.

Children were asked if they were in any pain at the time of the interview or in the past week on a scale of 0 to 10, with 10 being very painful. None of the PIC:TFK children indicated they were in pain at the time of the interview. When asked if they were in pain in the past week the PIC:TFK children on average had a 2.3 pain scale (standard deviation 3.0).

9 Surveys of Families Whose Child Died or Disenrolled

As of November 2006, 42 children had left the PIC:TFK Program. From the enrollment files, the main discharge reasons were as follows:

- death (9)
- families chose to disenroll (9)
- child no longer eligible (8)
- child moved out of the service area (8)
- transfer to long term care facility/ full hospice (4)
- hospice was unable to reach family to deliver PIC:TFK services (4)

The Institute contacted CMSN offices to confirm enrollment data and update contact information where necessary. In total, 11 parents completed the survey including two surveys where the child had died. Thirty-one families were unable to be surveyed for the following reasons: disconnected number/no forwarding number (13), 15-20 unsuccessful attempts to contact the family (8), hospice never provided services (5), refusal from bereaved parents (3), and family did not speak English (2).

Of the 11 parent respondents whose children left the PIC:TFK program, the mean age is 34 (standard deviation 7.4). Eighty-two percent of parents are White, 9% Black and 9% Hispanic. Equal numbers of parents have completed high school or some college (54%), while 18% have not graduated from high school, and 27% have completed an Associates degree or higher. Seventy percent of parents are married and in a two parent household. Parents reported that 46% of children are White, 9% Black and 46% Hispanic, and that 70% of children are male.

Respondents listed the main reason for disenrollment as follows:

- child no longer eligible (4)
- child moved out of the service area (3)
- death (2)
- transfer to long term care facility/ full hospice (1)
- hospice unable to reach family (1)

When asked what services their child had received, parents responded:

- Support counseling 64%
- Music therapy 27%
- Art therapy 9%
- Play therapy 0%
- Pain and symptom management 9%
- Personal care 0%
- Nursing care 45%

When asked what services the family members had received, support counseling was the most used service (55%). One family also received respite (in home and inpatient) and another family also received volunteer services.

Two parents report that they did not receive any services from PIC:TFK program and were unable to answer any further questions about their satisfaction levels with the program. Both wanted to receive services, but the family was either too busy or the child was hospitalized and died soon after enrollment. This parent subsequently participated in group bereavement counseling sessions offered by the hospice.

One hundred percent of parents responded that they were satisfied or very satisfied with the benefits offered in the PIC:TFK Program. All parents would recommend the PIC:TFK program to another family member or friend whose child had similar needs. No parent had filed a complaint. Two respondents wanted additional benefits such as more therapy and respite care.

At a Glance

“It is a wonderful program. I’d recommend it to anyone who qualifies -they are just wonderful, wonderful people”

Many families mentioned that the best thing about the program was the general level of support and that the PIC:TFK staff was able to connect families with other services. Some respondents commented:

“They help families, and put you in touch with other services you can use. They are there when you need them.”

“What I enjoyed most was the services the PIC:TFK program provided for the funding that they had. There’s not a lot available for special needs kids, especially in Florida. I think they have a lot of valuable information to share and resources to connect you with. The hardest thing in Florida is finding the correct people to talk to.”

Seventy-eight percent of respondents were satisfied or very satisfied with the nurse or therapist from the PIC:TFK program. When asked about the quality of care their child received in PIC:TFK, 89% rated it good to excellent.

“I like having the ability to have a nurse accessible to me and my son, any time of the day. We were very satisfied with the services and the staff was very caring. It is very comforting for a parent that is working to have someone knowledgeable to look after your child.”

Only one respondent reported being somewhat dissatisfied with their nurse, because “the nurse although nice, wasn’t really working out, she didn’t work on any therapies and didn’t have discipline.”

There were mixed responses about how available and flexible the staff were in providing services, and this seemed to be site dependent. At one site, respondents commented that “they were always there for me, whenever I needed to call someone for advice or help” or that they “worked around my schedule.” However at another site, respondents remarked that “the support counselor did not make frequent enough visits” or “the counselor was difficult to get hold of and sometimes I had to wait more than two weeks to get a call back or make an appointment.”

Although parents were overwhelmingly satisfied with the program, some were frustrated that they did not receive PIC:TFK services earlier. Parents commented that “it would have been helpful if they’d referred me to the program while my child was still in treatment” or “I think they need to make sure that parents know what services are available. I lived in Florida for a year before I even knew that the PIC:TFK program existed. Our case manager didn’t know much [about services available in our area] so I had to do all the research work.”

Parents reported high levels of satisfaction with the child’s personal doctor or nurse in the six months before leaving the PIC:TFK program. The CAHPS Composite Scores are as follows: family-centered health care- personal doctor or nurse (87); family-centered care- shared decision making (96); family-centered care- getting needed information (91); and, doctor communication (87). Although not included in the

CAHPS composites, respondents were also asked to rate their overall healthcare on a scale of 0 to 10, with 10 being the highest. Respondents gave their child’s healthcare a mean score of 8.5 (standard deviation 1.4).

The PedsQL questions were not administered to bereaved parents or parents of children in a coma or over 21 years. For the six parents responding to the PedsQL Generic Assessment, Composite Scores are: physical functioning (67), emotional functioning (82), social functioning (75), and school functioning (69). On the PedsQL Multidimensional Fatigue Assessment, Composite Scores are: general fatigue (85), sleep/rest fatigue (94), and cognitive fatigue (80). When asked the PedsQL Pediatric Pain Assessment questions, 63% of parents reported that their child was pain free in the past week.

Scores greater than or equal to 16 on the CES-D indicate the presence of current depressive symptoms. Of the 8 respondents, half scored greater than or equal to 16 and their mean score was 12.5 (standard deviation of 8.8). Parents of children disenrolled from the program reported an Impact on Family Scale score of 54.4. Although the impact on the family is considerable, these respondents report a lower impact score than the active PIC:TFK enrollees. Respondents also scored lower on all Impact on Family Scale composites compared with active enrollees, including: financial impact (9.4), familial burden (20.4), personal strain (15.7), coping (8.9), and sibling impact (12.0).

10 Parent Surveys of Comparison Children

In addition to interviewing parents and children in the PIC:TFK program, parents whose children were selected for the comparison group were interviewed. Using the primary and secondary diagnoses codes of the children currently in PIC:TFK, the Institute queried the Medicaid claims and encounter data to identify children with similar life-limiting diagnoses. All children in the comparison group are enrolled in CMSN and reside outside of the seven PIC:TFK areas. Children in the comparison group reside in counties with demographic and health infrastructure characteristics that are similar to the PIC:TFK sites.

Identifying a comparison group of children is important for the overall program evaluation. Because it is not possible to randomly assign children with life-limiting conditions to the PIC:TFK program or to a control group, an observational study using a comparison group of children with life-limiting conditions is the only option to effectively evaluate the program. Use of a comparison group can provide stronger evidence that the program intervention has an impact on the outcomes of interest (i.e., HRQOL, health care use patterns and expenditures, and families' experiences with the health care system) than simply observing the outcomes only for the children in the program.

In total, 41 comparison parents completed the survey. Their aggregate responses to the individual items are contained in the technical appendix accompanying this report. At baseline, the comparison children have higher functioning scores, as measured by the PedsQL core and fatigue scales, the children's illnesses have less of an impact on the family and fewer respondents are depressed, as measured by the Impact on Family Scale and the CES-D; respectively. Because the baseline results between the two groups are so dissimilar, the evaluation team is concerned that the comparison group is not appropriate relative to the children in the PIC:TFK program. The sampling methodology for the comparison group was based on the diagnoses found in the current PIC:TFK enrollees; yet the children in the comparison group are dissimilar.

Two strategies are being used to address this issue. First, as previously noted, the children enrolled in the PIC:TFK program do not reflect the full spectrum of diagnoses that were expected in this program. It is also possible that there are underlying differences in severity of illness that are not adequately captured in the claims data. The evaluation team will be providing diagnostic lists to the CMSN nurse care

coordinators every quarter in an attempt to assist with case finding and to standardize enrollment into the PIC:TFK program. Second, the sampling methodology for the comparison group is being refined. Pediatricians, faculty, and staff at the Institute have developed alternative sampling methodologies for identifying a comparison group, and these are being tested.

Summary and Recommendations

The Institute for Child Health Policy is making several recommendations for the PIC:TFK program. It is important to note that this is a complex and novel program in its second year of operation. Much has been accomplished as evidenced by the establishment of seven pilot sites with multiple program partners (CMSN Area Offices, Medical Directors, the provider community, and the families) and parental reports of positive experiences with the program. However, due to the newness and the complexity of the program, there are several areas for improvement. The recommendations made should be viewed in the context that this is a new and novel program that is in its early phases of development. The summary and conclusions for this report are aligned with the major sections.

ENROLLMENT TRENDS

Approximately 27% of the title XIX enrollee slots for the PIC:TFK program were filled as of January 2007, a marked improvement over the end of the 2005-2006 contract period. Each site continues to enroll children, with several sites growing by more than 100 percentage points since July 2006. The sites are to be commended for their hard work in identifying, contacting, and enrolling children. There were several reasons for increased enrollment during the 2006-2007 contract period. First, the PIC:TFK Program Director held an annual statewide meeting in March 2006 in central Florida. All PIC:TFK sites were required to attend and discuss strategies for enrolling children. Sites that were more successful at finding and enrolling children shared their strategies and the group discussed additional

possible outreach and enrollment approaches. Second, the PIC:TFK Program Director instituted site visits to discuss barriers to enrollment and strategies to address those barriers. Third, the PIC:TFK Program Director held monthly technical assistance calls where sites could seek additional help in enrollment, billing, and operations.

Even with the successful growth of the program, approximately 70% of the enrollment slots are unused. Identifying children for the program is complex because CMSN nurse care coordinators have large caseloads and enrollment for PIC:TFK must be considered on a case by case basis. In addition, the CMSN nurse care coordinators have different perspectives about when palliative care is necessary. We have the following recommendations to increase enrollment:

- Administrative data can be used as one tool to identify children for enrollment. When nurse care coordinators assume complete responsibility for identifying and enrolling children into the program, they may influence enrollment, depending on their perceptions about palliative care. To reduce bias; we recommend that the Institute query the Medicaid database for children with life-limiting conditions and provide a list of children to the PIC:TFK Program Director. The Program Director can distribute these lists to the CMSN offices, which are then responsible for following up with the clients. We further recommend that we obtain feedback from each site about which children on the list were enrolled and the reasons why children were or were not enrolled. This information can be used to monitor the quality of the identification and enrollment

At a Glance

Barriers to enrollment include:

- Nurse care coordinators have large caseloads
- Nurse care coordinators and referring physicians may have limited knowledge about pediatric palliative care
- Other organizations in the community serve the same population

process and to develop educational programs for the nurses and other providers as needed.

- Technical assistance calls and on site training should continue. Since turnover in CMSN nursing personnel can be significant, it is important to provide ongoing education and support about the program's purpose, goals, and procedures.
- A screening tool for PIC:TFK should be implemented at the point of

initial application for KidCare. Currently, Medicaid applicants answer questions about their children's health status using a variation of the Children with Special Health Care Needs Screener and are referred to the CMSN program based on the responses to the Screener. If the staff member believes that the child might also be eligible for PIC:TFK a flag is placed in the child's application. However, there is no structured screening tool for identifying children for PIC:TFK. The State should consider the development of a more structured tool that might allow more children to be identified at the time they apply to the KidCare Program.

- The State should be cautious about expanding the PIC:TFK program until procedures are better developed and implemented at the current sites.

HOSPICE SURVEY RESULTS

An essential ingredient for successful implementation of new health programs is the development of appropriate guidelines and the adherence of all parties to those guidelines. The goal of this hospice administrator survey was to assess whether hospices were in compliance with the PIC:TFK Implementation Guidelines and to provide baseline information on which to measure future success of the program. Hospices are in compliance in most areas; however there is room for improvement. We have the following recommendations.

- All hospices report that their staffing levels are adequate

to serve the current level of PIC:TFK enrollees and that they have strategies in place to ensure appropriate caseloads. Some hospices report that staffing is not an issue currently because of the low enrollment numbers. However staffing may become a challenge as the program expands and more children are enrolled. As part of the continuing internal review process, the PIC:TFK Program Director should continue to monitor staffing levels to ensure hospices are able to manage an increased enrollment volume, while providing all needed services. In addition, hospices should have formal procedures in place to assess staff levels as opposed to relying on informal reviews.

- Hospices are actively engaging with their partners in care, CMSN. However some hospices feel that the CMSN staff are passive and need to take a more active role in case management. Further, some feel that CMSN staff did not understand the importance of making referrals to the hospice and that this could cause difficulties enrolling children. This was also a finding from the Institute's 2005-06 report to CMSN and some of the recommendations from that report still stand²¹. Interviews were not conducted with CMSN nurse coordinators so their perspectives about their relationships with the hospice staff are not included. During the next evaluation year, interviews should be conducted with the CMSN nurse coordinators about their experiences with the program.

- The PIC:TFK Program Director should share best practice information to staff and provide ongoing training about operational issues.
- PIC:TFK program forms should be standardized to encourage adherence to best practices across the sites. These forms could be modeled on forms currently used at exemplary sites. For instance, one hospice has created their own forms which show how to develop a care plan, when the care plan should be reviewed, and who attended the care plan meetings.

At A Glance

Barriers for the hospices include:

- Adjusting staffing levels to offer all the PIC:TFK services
- Billing problems
- Planning staffing levels for future enrollment gains

- As the program continues to grow, all hospices should formally include the PIC:TFK program into their existing quality assurance protocol. We recommend that hospices incorporate routine audit schedules for PIC:TFK into their quality programs and formally document all quality assurance activities.
- Some hospices are not offering all available PIC:TFK services to their patients. These findings raise questions about whether staffing levels are adequate to meet the children's needs and to provide the full scope of services that are a key part of the program concept. The PIC:TFK Program Director or the Institute should discuss barriers and capacity building activities with hospices not currently offering all services.
- Some available services are underutilized. The PIC:TFK Program Director should examine why some hospices are not actively providing some services, particularly in the area of pain and symptom control; which is often overlooked in pediatric populations. In addition, the Institute is examining the Medicaid claims records for the PIC:TFK enrollees to ascertain if the children are receiving these services at locations other than the hospices.
- All the hospices have a grievance policy and compliance officers. It is currently unknown how and when this information is communicated to the PIC:TFK enrollees and this

will be investigated further. All hospices' should have grievance notification procedures that include giving written information to families.

- There were problems with billing during the first few months of operation. Although provider and services codes were specially created for the PIC:TFK program, some hospices initially had problems implementing a billing system and receiving reimbursement. This situation has improved, and the PIC:TFK Program Director is commended for working with the sites to ensure that they understand how to bill and that they are receiving payment. When billing errors were found, the PIC:TFK Program Director took immediate action to rectify the problem.
- However, improvement is still needed in the billing procedures. It is recommend that the PIC:TFK Program Director continue to formally audit all sites in 2007 and where applicable, communicate audit findings to the other sites to prevent any future oversights or billing problems.
- It is recommended that all hospices have formal billing and audit procedures in place and address any staff turnover issues that may impact performance.

QUALITY ASSESSMENT MONITORING

Appendix A contains the PIC:TFK Program Director's complete monitoring report and recommendations for improvement.

To summarize, the PIC:TFK program standards and guidelines will be updated to include standardized intake forms and documentation guidelines in the State's computer system. A corrective action plan was made for the three main quality indicators that were not met (hospices must offer all services, all children must have current recertification forms on file, and 33% of all enrollees must be newly diagnosed).

PARENT SURVEY RESULTS

Important lessons learned from the PIC:TFK parent surveys are detailed below:

- The PIC:TFK sites should perform quarterly updates, at a minimum, on their enrollment files. The enrollment files used for the survey were out of date with several children on the active enrollment list were deceased or discharged from the program. Given that the hospice personnel work with these families on a more frequent basis, we recommend that the CMSN and hospice personnel work together to keep the CMSN records up to date.
- The State should adopt a web-based enrollment file or create a data entry screen in the CAPS computer system to easily access and update the enrollment files.
- When families receive a copy of their care plans, a statement informing them that they may be contacted to participate in an evaluation of the PIC:TFK program should be included. This may help to improve response rates.

In terms of survey results, the following summary and recommendations are provided:

- The majority of PIC:TFK families (86%) were very satisfied or satisfied with the program benefits and the overall program quality.
- Thirty-nine percent of PIC:TFK parents expressed an unmet need such as: massage therapy, music therapy (hospice was not providing this service), diapers, pet therapy, and more services for siblings. Volunteer services that include pet therapy should be considered. In addition, the services rendered to siblings should be reviewed to ensure that currently covered services are provided to this important group.
- The PIC:TFK children primarily received support counseling (55%) and nursing care (52%), while the families received support counseling (55%) and in home respite (16%). PIC:TFK sites should be reminded of the breadth of services offered and encouraged to offer as many services as needed and that are in accordance with the program model. Furthermore, we recommended a bi-annual review of the services utilized and an annual review of parents' reports of unmet needs to assist CMSN in assessing the benefit and program design.
- Over 50% of the PIC:TFK families learned about the program from their nurse care coordinator. While the role of the CMSN nurse coordinator in identifying potential enrollees is a key part of the program design, it is recommended that the nurses also work with other agencies and local pediatric providers to identify children.
- To ensure that all ethnic and racial groups are reached, it is recommended that all PIC:TFK materials are available in Spanish and Creole and that each site has a designated contact for families who do not speak English. Furthermore, sites should be encouraged to increase enrollment of minority populations in their area by using outreach strategies that are most beneficial for minority families. We further recommend that the Institute contact families who refused to participate to identify potential barriers or concerns that these families have to program participation.
- Results from the CAHPS composites show that families in PIC:TFK rated their family-centered care- shared decision making, doctor communication, and family-centered care- personal doctor or nurse about the same (composite score of 84). However, the family-centered care- getting needed information was higher (89). These scores indicate that families have positive health care experiences with their children's providers in these areas.
- From the PedsQL Generic Composite Scores, PIC:TFK parents rated their children's HRQOL highest for emotional (61), social (52), and school functioning (49) and lowest for physical functioning (32).
- Using the Impact on Family Scale, parents report financial strain, loss of work, and disrupted relationships with their other

children due to their sick child. These results emphasize the need for support counseling and for all family members.

CHILD SURVEY RESULTS

Nine children completed the survey. The number of completed surveys is limited by the number of children who can physically and mentally participate and by the number of parents who allowed the interview to occur. Therefore, we have no specific recommendations in regard to completed survey numbers. Most children who completed the survey were able to answer all the questions. We will continue to encourage parents to allow children to participate in interviews to gather more information about children's perceptions of their care and their HRQOL.

DEATH OR DISENROLLEE SURVEY RESULTS

Families of children who had died or disenrolled from the PIC:TFK program were very satisfied with the program. Survey findings include:

- Parents were very satisfied with the benefits offered in the program, the quality of care, and the PIC:TFK nurse/therapist. All respondents would recommend the program to another family member or friend. As with current PIC:TFK enrollees, nursing and support counseling for both the child and parent were the most common services received.
- Compared with active PIC:TFK enrollees, parents had slightly better emotional functioning and there was less impact of the child's illness on the family.

Summary and Recommendations

In many cases the hospice is continuing to provide services to children who lost their CMSN eligibility.

- These survey results may not represent the views of all parents whose children died or disenrolled from the program. Attempts were made to contact all families, however current contact information was not available for many families who had moved or lost their CMSN coverage.

COMPARISON SURVEY RESULTS

The final recommendations of the report deals with the sample methodology used to identify children for the comparison group:

- As discussed, the preliminary findings indicate that children in the comparison group of have higher functioning scores, as measured by the PedsQL Fatigue and Core modules, and their parents have fewer financial, emotional, and depressive problems, as measured by the Impact on the Family Scale and CES-D modules.
- It is possible that the comparison group is not appropriate because they are so different from the PIC:TFK at baseline. For the comparison group to be valid the children must be similar to the PIC:TFK children in regard to diagnoses, severity of illness, and demographics with the primary difference being that the comparison children are not enrolled in PIC:TFK. Since the results show that children in the comparison group are healthier

and their families are impacted less by their children's illness, the comparison group may not be appropriate.

- The comparison group was chosen using the same diagnoses observed among the PIC:TFK Program enrollees. This suggests that enrollment in the PIC:TFK program is complex and there may be important differences between the comparison group and the program enrollee group based on severity of illness and other factors. Given that PIC:TFK children have markedly lower functioning scores, this might indicate that PIC:TFK children are being selected at the later stages of illness or are those children who are the least responsive to therapies. This is not consistent with program goals that focus on enrolling children throughout the illness course including those who are newly diagnosed and those who are responding to active treatment.
- As previously described, the evaluation team has developed a strategy to assist the CMSN nurse coordinators with better case finding for the PIC:TFK Program and also is refining their strategies for identifying the comparison group of children.

Appendix A. PIC:TFK Program Director's Quality Monitoring Report

DESCRIPTION

In July 2005, Florida Partners in Care: Together for Kids (PIC:TFK) program for children with life-limiting illnesses began. During the waiver period of 2005-07 the program reviewed and refined the programs implementation guidelines, operational processes, and developed a quality assurance plan. In collaboration with the Institute for Child Health Policy (IHP) at the University of Florida (UF) and Medicaid, programmatic technical assistance (TA), training, surveys, interviews and monitoring visits were conducted. The process began with surveys to Children's Medical Services Network (CMSN) offices and hospice agencies to evaluate whether or not the programs were adhering to the PIC: TFK program implementation guidelines, how children were identified for referral to the program, and parent/child interviews. The process ended for this evaluation period by conducting TA and monitoring visits to evaluate service provision, billing of PIC:TFK services. Interviews were held with each program site management and staff to gain an understanding of the local systems of care that had been developed for children and their families with life limiting conditions, to ensure that supportive services are: Accessible, and responsive to the needs of child and family. Information was collected and analysis performed regarding the following:

Performance Indicators were developed to ensure the adherence to the Children's Hospice International Program for All-Inclusive Care for Children

and Their Families (CHI PACC) Standards of Care and Practice Guidelines, May 2003 and the requirements set forth in Medicaid 1915 (b)(3) waiver which provides the authority for the program to provide pediatric palliative care services that include pain and symptom management, counseling, expressive therapies, respite and hospice nursing and personal care services to children and their families who are enrolled in the CMSN.

The focus was to define programmatic outcomes for:

1. **Access to Care**
2. **Quality of Care**
3. **Cost Effectiveness**

The following Access to Care structural and administrative indicators will measure access to the programs services.

1. 100% PIC:TFK Hospice sites will operate in accordance with requirements established in the Pediatric Palliative Care - Criteria for PIC:TFK Participation.
2. 100% of the children enrolled in PIC:TFK will have a current Certification or Recertification Form designating medical eligibility for PIC:TFK from the child's primary care physician.
3. 90% of the PIC:TFK Assessments will be completed by Hospice within 10 working days from the day the referral is received by Hospice from the CMSN.

4. 100% of children enrolled in PIC:TFK will have PIC:TFK services authorized by the child's primary care physician.
5. 33% of children with life-threatening conditions and who are enrolled in PIC:TFK will have been newly diagnosed within three months of enrollment.
6. 95% of professional staff of Hospice and the CMSN who provide direct care or contact in the PIC:TFK program will complete a nationally recognized pediatric palliative care curriculum within 24 months of the initial assignment to the PIC:TFK program. 100% of the modules in the NHPCO Pediatric Palliative Care Curriculum, the ELNEC Pediatric Palliative Care Curriculum or any curriculum approved in advance by the PIC:TFK Steering Committee.

The following Quality of Care indicators are intended to ensure that children with life-limiting conditions and their families receive PIC:TFK services that are responsive to their needs.

1. 100% of the children enrolled in PIC:TFK will have a coordinated, comprehensive Care Plan
2. 100% of bereaved families will be offered bereavement follow-up within seven working days of the death of the child. Follow-up may extend for twelve months and include individual, family or group counseling, mailings and invitations to memorial services and activities.

3. 100% of the families, including age-appropriate children and youth enrolled in PIC:TFK, will receive appropriate information about the disease/condition, treatment, symptoms and services.
4. 100% of the PIC:TFK children will have a health care delivery system that demonstrates a coordinated effort to provide curative and supporting care.
5. 100% of the PIC:TFK Care Plans reflect child/youth orientation and a family-centered approach to care.

performance in meeting the access indicators. Discussion will include only the indicators that did not meet 100 %.

- Access 1: 100 % of PIC:TFK Hospice sites will operate in accordance with requirements established in the Pediatric Palliative care Criteria. One of the 6 hospice sites reviewed did not offer all services to program participants. This program site was advised to build the capacity to provide all PIC:TFK services.
- Access 2: 100% of the children enrolled in PIC:TFK will have a current Certification or Recertification Form designating medical eligibility for PIC:TFK from the child's primary care physician. One of the 6 CMSN sites reviewed did not have current recertification forms. This program site was advised to have supervisor to review cases quarterly to ensure this indicator is met.
- Access 5: 33% of children with life-threatening conditions and

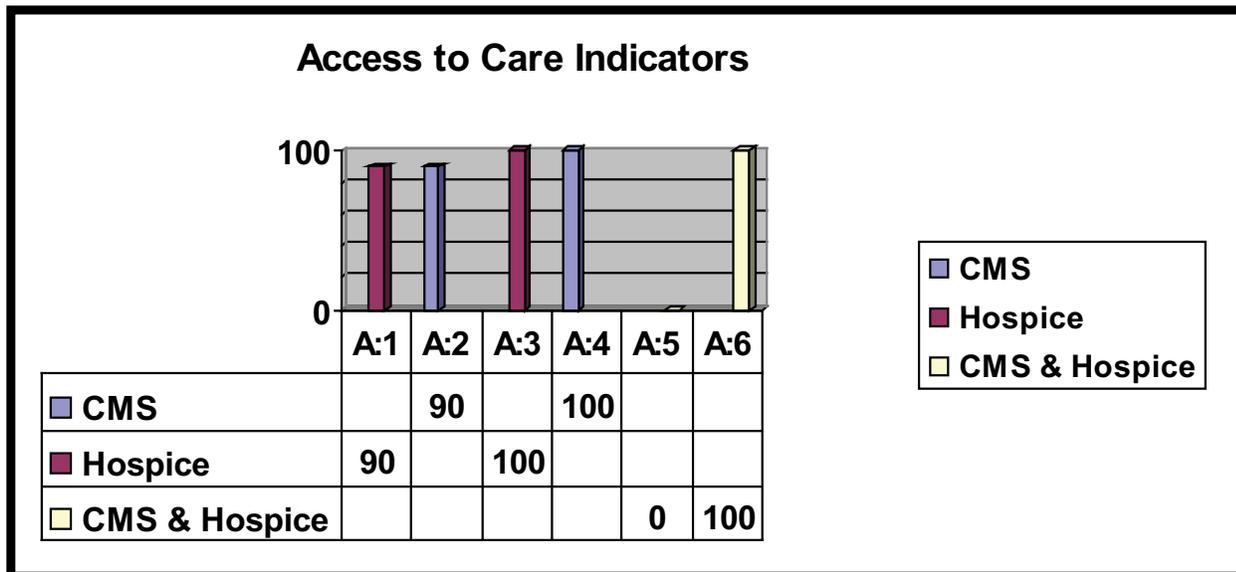
who are enrolled in PIC:TFK will have been newly diagnosed within three months of enrollment. None of the sites reviewed met this access indicator. Most children who have been enrolled into the program have been at Mid Stage which is defined as children who are 4 months or more post-diagnosis and who are on active treatment and/or intervention. Discussion at each site visit revealed why this might be occurring. Some of the reasons shared were, by the time the children are enrolled in CMSN they are often 3 months post diagnosis, families are overwhelmed when a child is first diagnosis with a life-limiting condition and are not receptive of hospice services. In March of 2007, the 2nd Annual Partnership Meeting will be held, during this meeting strategies will be shared on how to engage families and identify children at Newly Diagnosed Stage. Collaboration strategies will also be discussed with Neonatal Intensive Care Units and Physicians.

ANALYSIS ACCESS TO CARE

A technical assistance visit and monitoring visit was conducted for all program sites during the wavier period of 2005-2007.

DISCUSSION

Technical assistance was provided to program staff and management staff on ways to improve their

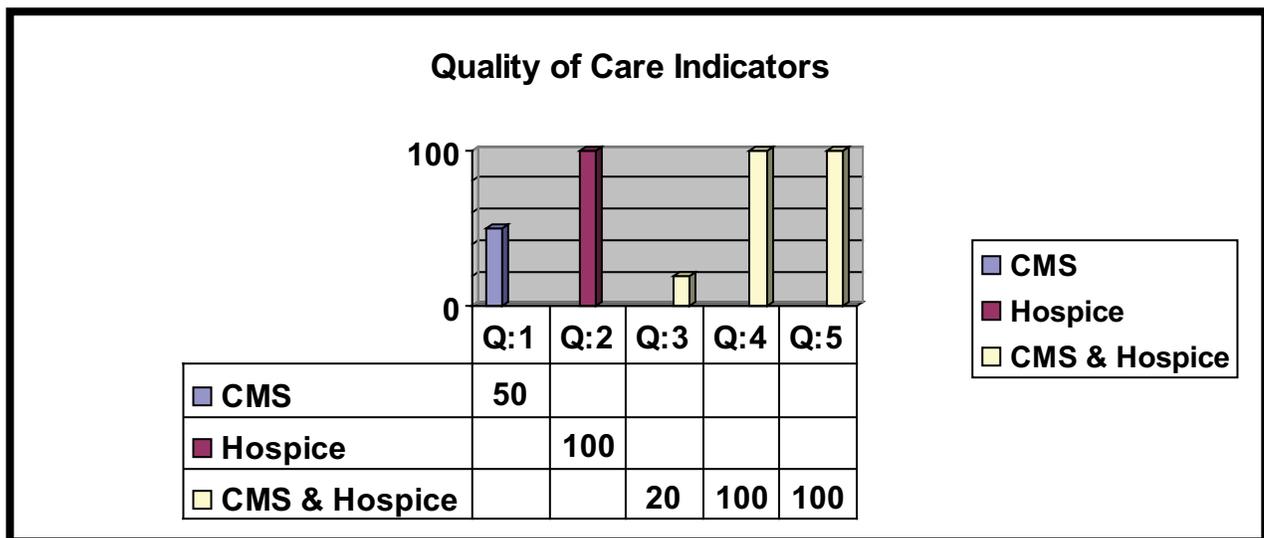


ANALYSIS QUALITY OF CARE

A technical assistance visit and monitoring visit was conducted for all program sites during the wavier period of 2005-2007

- Quality 3: 100% of the families, including age-appropriate children and youth enrolled in PIC:TFK, will receive appropriate information about the disease/condition, treatment, symptoms and services. Only 20% of

- Develop standard forms for administrative and operational processes.
- Develop documentation guidelines for CMSN care coordinators to follow in the CAPS system.



DISCUSSION

Technical assistance was provided to program staff and management staff on ways to improve their performance in meeting the quality of care indicators. Discussion will include only the indicators that did not meet 100 %.

- Quality 1: 100% of the children enrolled in PIC:TFK will have a coordinated, comprehensive Care Plan. Half of the CMSN Care plans reflected documentation of PIC: TFK services, referral and follow up. The need to standardize documentation in the Child Assessment and Plan System (CAPS), and to revise the data system to include program information. Revisions will be made in the system and instructions provided to CMSN care coordinators by July 2007.

the charts reviewed met this indicator. A standardize intake form will be developed that will include whether or not the family was asked if information is requested/provided. This will be implemented July 2007.

TECHNICAL ASSISTANCE AND IMPROVEMENT PLAN

The PIC:TFK program operates in compliance with most indicators and the Implementation Guidelines. To ensure that these indicators and guidelines are met during the next waiver period, several recommendations have been made. They are as follows:

- Include PIC:TFK indicators in the performance measurement reports that CMSN area offices must report on each quarter.

- Develop a system to identify children who are potentially eligible for the program, and track the process of referral and acceptance into the program.
- Develop and conduct program training for new staff have been hired by both CMSN and Hospice.
- Develop new marketing materials that consider literacy level, and health literacy and that are visual appealing.

Footnotes

1. For a history of the program leading up to implementation, see “Partners in Care Together for Kids Implementation Guidelines: Operational Standards, Policies, and Protocols,” 2007.
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13. National Hospice and Palliative Care Organization. NHPCO’s Facts and Figures- 2005 Findings. Available at: <http://www.nhpc.org/files/public/2005-facts-and-figures.pdf>. Accessed Mar 20 2007.
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17. Numbers add and exceed 100% since many clients used more than one service. [add this sentence before the sentence “When asked what services the family members had received, parents responded:”]
18. Stein R, Riessman C. The Development of an Impact on Family Scale: Preliminary Findings. *Med Care*. 1980 Apr; 18(4):465-72.
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20. Numbers add and exceed 100% since many clients used more than one service.
21. Institute for Child Health Policy. Children’s Medical Services: Partners in Care Together For Kids Report. Contract Period 2005-2006.