



# The Importance of Integrated Services

A system of services is a family-centered network of community-based services that is designed to promote the health and well being of CYSHCN and their families. Ideally, community-based service systems are organized so families can use them easily. Care coordination, access to a medical home, family-centered and culturally competent services are considered key elements of coordinated services for families of CYSHCN. However, many families of CYSHCN face frustration accessing services. Eligibility requirements, policies, procedures, and multiple locations of services can leave families feeling overwhelmed. There are often gaps in services due to agencies that provide limited services or duplication in services from multiple coordinators and service plans. Families may also need to travel great distances to obtain specialized services.

The examples in the following sections, from medical home, care coordination, family-centered care, to cultural competency, as well as the common application forms found in the health information technology section, all address some piece of a coordinated system of care—although no state or community addresses all issues equally well. The following models of care often use strategies recommended by Champions for Inclusive Communities for developing coordinated services: including the use and development of interagency councils, partnerships with coalitions, supporting the development of family leadership and family-directed programs, and promoting linkages at the local and state level. For local level examples, please refer to the Star Communities on the Champions website: [www.Championsinc.org](http://www.Championsinc.org).

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# Palliative and Respite Care

Although many states report that CYSHCN and their families have a high demand and need for palliative and respite care, these services are often underfunded. According to experts, effective palliative and respite care should be tailored to the needs of the participants. The services should also be culturally competent since they will be used by a diverse community. The models below demonstrate effective approaches to palliative and respite care.

### FLORIDA: PARTNERS IN CARE

#### Public

#### Emerging Practice

Florida has a diverse population that is similar to California, and leaders of California's Title V CYSHCN program have shown particular interest in its palliative care model.

In July 2005, Florida's Partners in Care (PIC) program for children with life-limiting illnesses was created. This was a result of the approval of the first federal Medicaid waiver granted to provide this comprehensive service delivery system designed to enhance the quality of life for this vulnerable population. Prior to the establishment of the PIC program, children with life-limiting illnesses received hospice care under a Medicare model, which precluded curative treatment. Because the lifespan 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.

**System of Care:** This program is targeted to children/adolescents who are 0-21 years of age and enrolled in the CMS (Children's Medical Services) network under Medicaid or CHIP (KidCare). Each participant must be certified annually by their primary care physician to have a life-threatening condition.

The overall objectives of this program include:

- Enabling children with potentially life-limiting conditions and their families to access a support system that is continuous, compassionate, comprehensive, culturally sensitive and family centered from the point of diagnosis, with hope for a cure, through the provision of end-of-life care if needed
- Identifying and removing barriers that prohibit access to pediatric palliative care that is a compassionate, comprehensive, coordinated blend of services that support both curative and comfort care while preserving the quality of life for children with potentially life-limiting conditions
- Supporting families and caregivers of children with potentially life-limiting conditions as they work to manage their lives given the circumstances brought about by the child's illness

**Financing:** PIC is the first publicly financed health program for children in the nation to utilize a pediatric palliative care model that integrates palliative with curative or life-prolonging therapies. PIC is based on the Children's Hospice International Program for All-Inclusive Care for Children and their Families national model of pediatric palliative care, which strives to provide a "continuum of care for children and families from the time that a child is diagnosed with a life-threatening condition with hope

for a cure, through the bereavement process, if cure is not attained.”

**Evaluation:** PIC, which is funded and sustained by Medicaid, currently serves more than 300 children and is in the process of expanding to new sites. Some of the services provided by PIC are pain and symptom management, respite care and hospice nursing care. An evaluation of the PIC program is under way.

**Will it Work in California:** Florida’s experience implementing a pediatric palliative care program may be of special interest to California since it has recently received federal approval to implement a similar type of program. California’s program will start enrolling children in Fall 2009 (<http://www.childrenshospice.org/>).

*Source:* [http://ahca.myflorida.com/Medicaid/quality\\_management/mrp/contracts/med052/annual\\_report\\_2007-08.PDF](http://ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/annual_report_2007-08.PDF). Retrieved August 13, 2009.

## **OREGON: RESPITE CARE FOR THE LIFESPAN**

### *Public Promising Practice*

Oregon’s Lifespan Respite Care Program has been mentioned as a model by numerous experts and in 1991 was identified as one of the five best practice models among 33 programs surveyed (Family Caregiver Alliance, October 1999).

**System of Care:** Created by legislation passed in 1997, the Oregon program directs the Department of Human Services (DHS) to assist local communities in building respite access networks for family and primary caregivers—regardless of age, income, race, ethnicity, special need or situation. DHS, through the Oregon Lifespan Respite Care Program, contracts with private non-profit, for-profit or public agencies in communities throughout the state. Each of these agencies acts as a single local source of information, referral and access to local respite care services. Respite care is one of the most identified services requested by primary caregivers.

**Financing:** This program is funded and sustained primarily by Medicaid.

**Evaluation:** In 2007, the Legislature approved funding for DHS to renew a strong commitment to ensure that Community Lifespan Respite Care Program partners are able to coordinate respite care to family caregivers. During 2007-2008, 4,000 people accessed respite services. Currently, 22 networks in Oregon provide the following services in all 36 counties:

- Recruitment and training of respite care providers
- Coordinating necessary respite-related services based on each caregiver’s and family’s needs
- Information and referral to respite-related services
- Linking families with potential respite care payment resources

**Will it Work in California:** The respite care program in Oregon gives local communities control over the services they provide, thus it may be of interest to California, given its diverse communities and county-based systems. Also, this program is an example of a public-private partnership.

*Source in addition to expert interviews:*  
[http://www.oregon.gov/DHS/respite/about\\_us.shtml](http://www.oregon.gov/DHS/respite/about_us.shtml). Retrieved July 31, 2009.

## **WASHINGTON: FAMILY-CENTERED AND CULTURALLY COMPETENT PEDIATRIC PALLIATIVE CARE**

### *Private Emerging Practice*

The Seattle Hospital for Children offers palliative care for children and teens with potentially life-limiting or complex conditions through its Pediatric Advanced Care Team (PACT) program.

**System of Care:** This program, which began in 1997, includes a nurse, doctor, social worker and chaplain, who work closely with patients and families to craft a palliative care plan that meets their needs. The team also consults with the child’s primary care physicians so that they are involved in the process. Another component of PACT is ensuring that families are aware of resources and information they need.

Understanding and respecting patients’ cultural diversity is an important part of PACT. Team mem-

bers work closely with staff from the Children’s Center for Diversity and Health Equity to better understand patient families from different backgrounds and cultures. Additionally, PACT staff has been trained by the Initiative on Pediatric Palliative Care (IPPC), which encourages staff members to practice cultural humility.

**Financing:** There is no fee for PACT patients since PACT services are supported by a combination of hospital administrative funds and funds allocated from a private endowment dedicated specifically to palliative care. Program staff is currently working on developing an appropriate quality metric to serve as an evaluation tool for its services. This metric will take into account the unique and challenging situation these patients and their families face.

**Will it Work in California:** This program is an example of how a hospital system approaches palliative care for its patients. It includes aspects of family involvement and cultural competency as the foundation for patient care. It may be of interest to the foundation because of its close relationship with children’s hospitals in California.

*Source in addition to expert interviews:* [http://www.seattlechildrens.org/our\\_services/palliative\\_care\\_consultation/](http://www.seattlechildrens.org/our_services/palliative_care_consultation/). Retrieved August 12, 2009.