

# **Project “Runaway”**

## **Designing the New Discipline of Pediatric Palliative Care**

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# Objectives

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- ❑ Understand the current status of the discipline of Pediatric Palliative Care
  - ❑ Present a model for the future of the discipline as an academic-community partnership
  - ❑ Realize the competing professional perspectives as to how the discipline should develop
  - ❑ Define an agenda for collaborative research
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# Epidemiology

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Nearly 75,000 children and transitioning young adults die each year.

- Sixty percent of deaths are in children under 12 months of age—with nearly half dying from congenital and chromosomal defects, peri-natal conditions and abnormalities.
  - Children ages 1-19 years account for 40% of deaths—with nearly 25 percent dying from congenital and chromosomal anomalies, malignant neoplasms and abnormal clinical findings.
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# Scope of Care

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Palliative care seeks to:

- ❑ Manage symptoms and relieve physical and emotional distress produced by medical conditions.
- ❑ Help children, siblings and extended families live as normally as possible and improve their quality of life.
- ❑ Provide timely and accurate information to support children, families and caregivers in decision making.

Hospice care seeks to:

- ❑ Prepare the child and family for death by supporting them and their caregivers through the final months of terminal medical conditions.
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# Pediatric Palliative Care

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Care for children demands an understanding of, and attention to:

- ❑ The developmental imperative of childhood, from infancy through adolescence and transition into adulthood.
  - ❑ Children's social and emotional milieus that differ from those of adults.
  - ❑ The context of family and the impact of illness on the well-being of siblings.
  - ❑ The physiology of children that differs from that of adults, including the subjective and physiologic experience of pain.
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# Pediatric Palliative Care

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Care for children demands an understanding of, and attention to:

- ❑ The pharmacologic management of illness related pain and symptoms, including the necessity to adapt adult regimens to children.
  - ❑ The life course of ill children.
  - ❑ The breadth of pediatric services related to palliative care, including treatment of the primary disease, treatment of associated illnesses and symptoms, and enhancing length and quality of life.
  - ❑ The different types of illnesses affecting children, e.g., genetic and congenital problems and disorders.
  - ❑ The developmental status of the science, art and delivery of pediatric palliative and hospice care that are just beginning to evolve.
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# Challenges

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Challenges to providing holistic Palliative Care:

- ❑ Every sector of a community must respond if we are to succeed. Pediatricians must be prepared with the skills to meet the medical needs of chronically ill and medically complex children.
  - ❑ Insurance companies must cover the entire cost of pediatric care, including medical, mental health, psychosocial and respite services.
  - ❑ Hospitals must provide interdisciplinary services in specialized units, with uninterrupted linkages to community-based services.
  - ❑ Schools and other venues where children participate must be prepared to nurture affected children and families.
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# Elements of the Discipline

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## Elements of Pediatric Palliative Care

- Clinical
  - Research
  - Training
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# Clinical

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Clinical Pediatric Palliative Care programs must:

- ❑ Span the continuum of community-through hospital based care.
  - ❑ Be designed to provide comprehensive and compassionate palliative and end-of-life care to children with life-limiting or life-threatening illnesses and their families.
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# Clinical

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## Elements of Clinical Programs

- ❑ Be interdisciplinary
  - ❑ Ensure organizations are linked in a continuum of care
  - ❑ Relieve suffering, provide comfort and improve the quality of all aspects of a child's life, and that of their family's
  - ❑ Programs must include at a minimum--medical, nursing, mental health, social service, child life and spiritual support.
  - ❑ They must include pain and symptom management, as well as, medical consultation; mental health, psychosocial and spiritual support and counseling; family respite; assistance with financial issues; case management; and bereavement and grief support.
  - ❑ Special attention is paid to the needs of the siblings.
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# Research

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Programs must:

- ❑ Advance the knowledge base for pediatric palliative and hospice care.
  - ❑ Engage in scholarly activity.
  - ❑ Generate an evidence base related to the interdisciplinary medical and community-based care of children and an in-depth understanding of how to best provide these services.
  - ❑ Expand the breadth and depth of what is known about pediatric palliative and hospice care, how to provide optimal services and approaches to training health professionals.
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# Training

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Training must be:

- ❑ Interdisciplinary including the medical and social sciences, e.g., physicians, nurses, social workers, psychologists, child life specialists, clergy, etc.
  - ❑ Practitioners must be educated through their care of their patients.
  - ❑ Elements must include:
    - Rotations for pediatric and family medicine residents.
    - Fellowship training in pediatric palliative and hospice care is required to provide advanced specialty training to pediatricians.
    - Chaplain mentors for chaplaincy students.
    - Nursing and Social work student rotations.
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# Academic-Community Partnerships

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Academic-Community partnerships are required to advance the principles and practice of this new discipline of Pediatric Palliative Care.

- ❑ Serve as models for communities to develop pediatric palliative programs, in particular as the specialty of palliative care becomes firmly rooted in pediatrics.
  - ❑ Ensure a seamless continuum of care across all boundaries of the medical system—from inpatient through community-based care.
  - ❑ Establish a secure base in area hospitals and among subspecialists.
  - ❑ For the development of training programs.
  - ❑ To advance scholarly endeavors.
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# Academic-Community Partnerships

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The academic-community partnership enables:

- ❑ Communities to leverage the assets of both sectors to establish a “whole” that is much larger than the “sum of its parts.”
  - ❑ The ability to work in the community with community practitioners and in the hospital with subspecialists.
  - ❑ The integration of professional education and relevant research into the core of the program.
  - ❑ The integration of service, education and research to provide a solid platform to sustain and build programs.
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# Academic-Community Partnerships

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## Resource Generation:

- Philanthropy
  - Grants
  - Contracts
  - Billing: Private and Public Sector
  - Waiver Programs
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# Community PedsCare

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- Started 10 years ago
  - Academic-Community Partnership
    - Community Hospice NE
    - Wolfson Children's
    - University of Florida
    - Nemours Children's Clinic
    - Community
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# Program

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A pediatric palliative and hospice program within a non-profit organization (Community Hospice NE) for children with life-limiting and life-threatening conditions.

The program offers in-hospital and in-home medical, nursing, psychosocial, spiritual, volunteer and other services to support, comfort and care for children and their families.

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# Community PedsCare

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- ❑ Children under age 21 who desire palliative or hospice care (162 patients served in 2007. Currently 110 children and families in the program)
  - ❑ Patients residing within five counties of Northeast Florida – Baker, Clay, Duval, Nassau, St. Johns
  - ❑ Patients admitted to Wolfson Children's Hospital and Shands Jacksonville
  - ❑ Perinatal and newborn patients in all area hospitals with labor and delivery services
  - ❑ Children's Medical Services Network (CMSN) patients
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# Services

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- ❑ Palliative and hospice home visits by physicians, nurses, social service generalists, child life specialist, spiritual counselor and volunteer.
  - ❑ Inpatient hospice care, available at Wolfson Children's Hospital, Jacksonville
  - ❑ Pain and symptom management
  - ❑ Hospice and palliative consultations at homes and hospitals in service area
  - ❑ Medical supplies for palliative patients who have no other provision or payor source
  - ❑ Durable medical equipment and medications for hospice patients
  - ❑ Grief and bereavement support and counseling to the sick child and their family members
  - ❑ Counseling to the sick child's teachers and classmates
  - ❑ Home Health services
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# Hospital-Based Service

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- Palliative Care Service
  - 10 bed Palliative and Progressive Care Unit
  - Section in Hospital Staff
  - Pain and Symptom management Service
  - Rehabilitation
  - PICU, NICU, Perinatal Programs
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# Continuum of Care

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- ❑ Medical Director for Hospital and Community Services are the same
  - ❑ Program staff provide continuity
  - ❑ Funding from Community, Academic and Hospital sources
  - ❑ Pain and Symptom Management
  - ❑ UF faculty provide collaborative academic environment
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# Personnel

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- ❑ Two Physicians (University of Florida Faculty)
  - ❑ Two nurse managers
  - ❑ Three primary nurses
  - ❑ Three social service generalists
  - ❑ One child life specialist
  - ❑ One inpatient liaison nurse
  - ❑ One volunteer coordinator
  - ❑ One spiritual counselor
  - ❑ Access to Community Hospice pharmacists, bereavement staff, and other resources
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# Academic Pursuits

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- Education
    - Resident rotations
    - Clergy
    - Social Work
    - Fellowship being planned
  
  - Research
    - Externally funded projects
    - Formative and Summative
    - Economic Impact
    - Health Related Quality of Life
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# Community Participation

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- Professional Advisory Committee which includes:

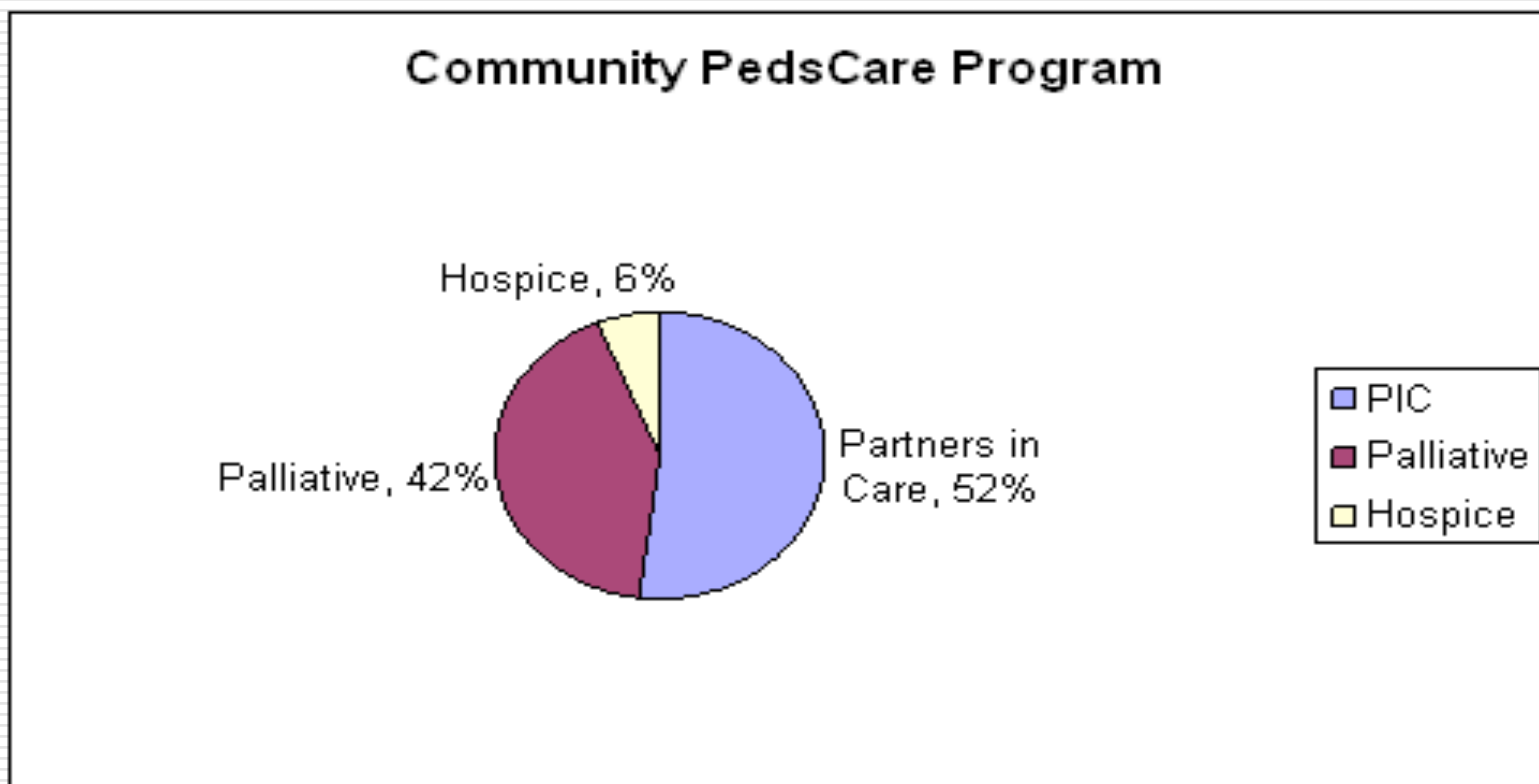
A social worker, a senior chaplain, the chief medical officer and chief pediatric hematology and oncology physician of the area's children's hospitals, and patient care service administrators, pediatric physicians and administrators from the University of Florida.

- Community Advisory Board

Comprised of community partners and parents to ensure the relevance of the program to the needs of the families and the community.

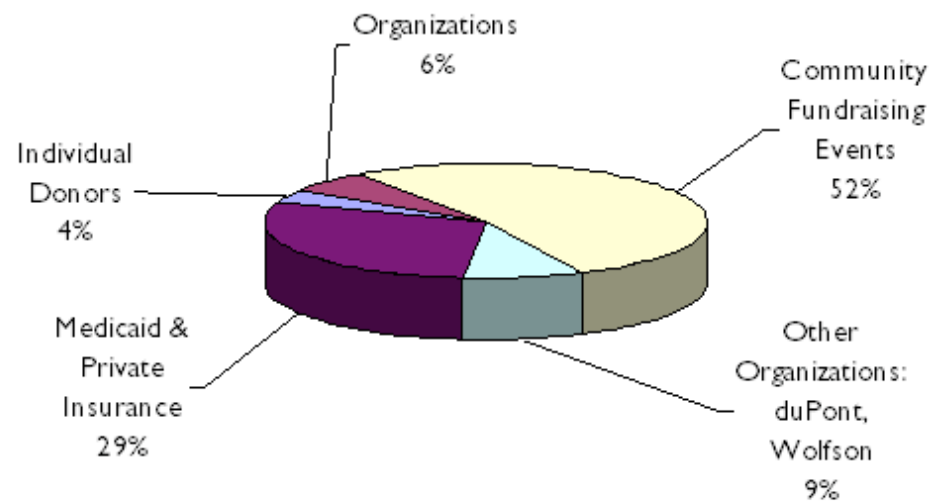
- Youth Advisory Board
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# Community PedsCare



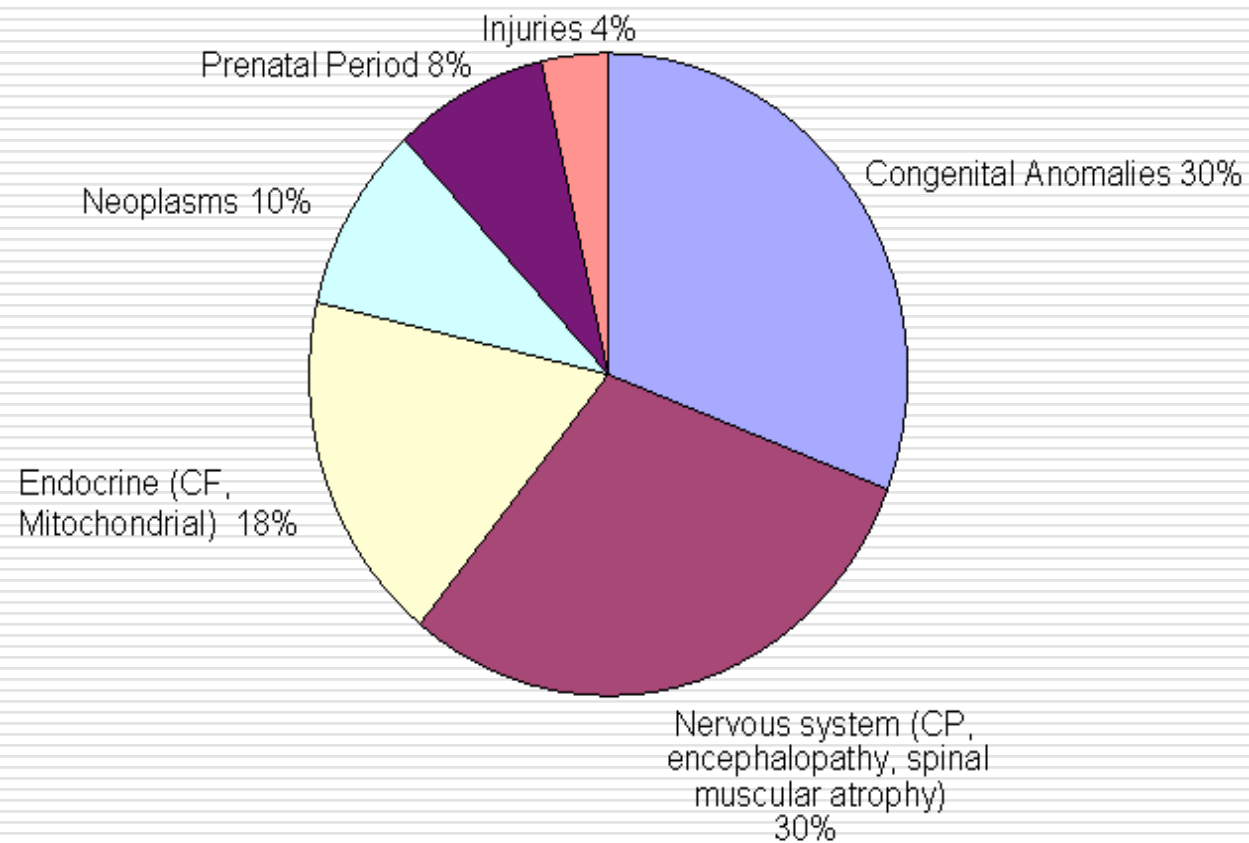
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## Expenses

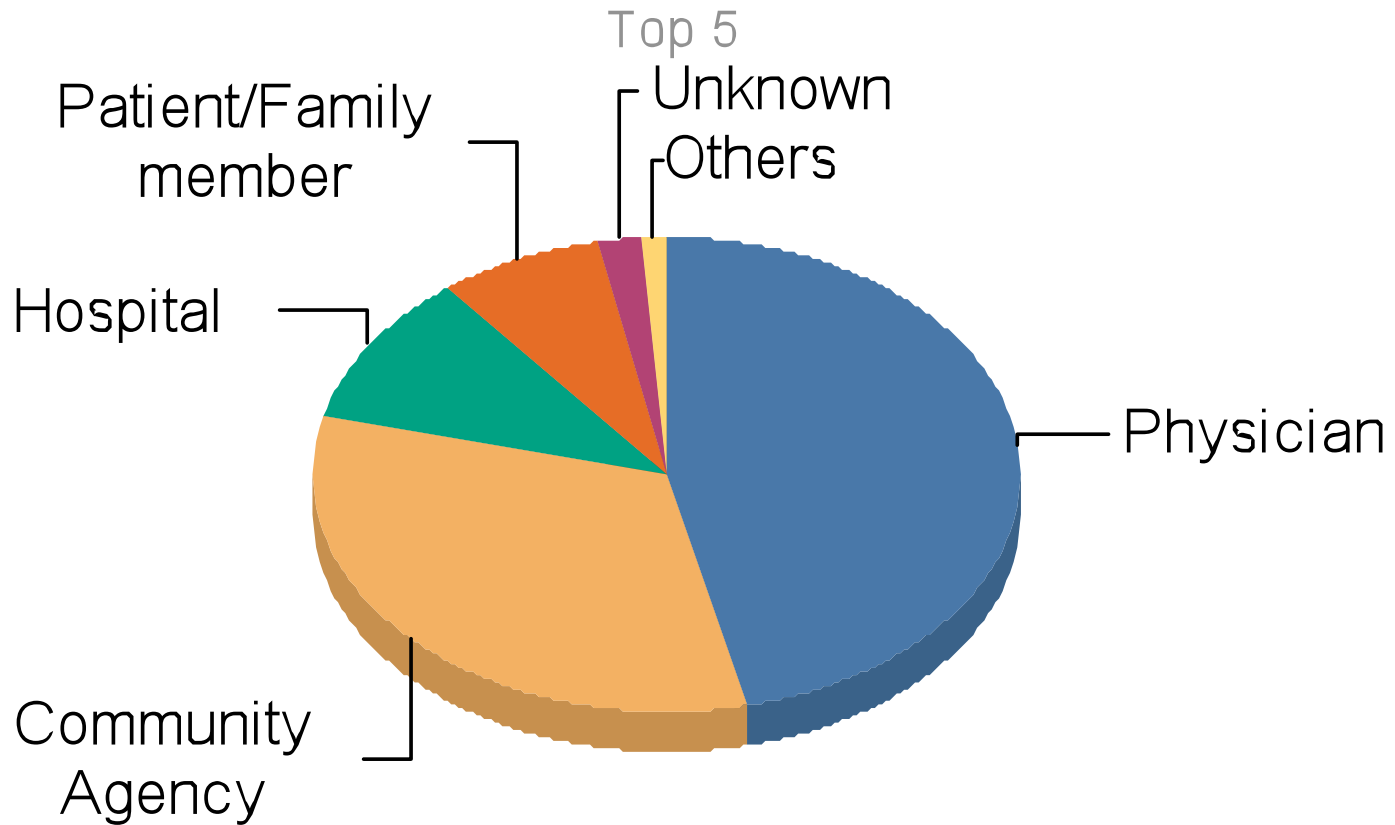


## Community PedsCare Patients by Diagnosis 2.08-8.08

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# PedsCare Referral Sources



# The Horizon

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We need to turn this challenge into opportunity. We have:

- ❑ The chance to develop a new child health discipline to serve our children and families.
  - ❑ The opportunity to develop national models of care.
  - ❑ The possibility to integrate professional education in pediatric palliative care into a national model for service-learning
  - ❑ The prospect to integrate research into practice as a prototype for academic-community partnerships
  - ❑ The opportunity to engage the community and professional partners in the development of this new discipline of Pediatric Palliative Care.
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# Challenge

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But we are at a crossroads in the development of this new discipline of Pediatric Palliative and Hospice Care that will define its future.

A crossroads that will require diplomacy, compromise and consensus if it is to emerge as the holistic continuum of care that will optimize its contribution to the health and well-being of children and families.

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# Challenge

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Hospital-Based → **Board Certification**  
Hospitalist, PICU, NICU

Community Services →  
Interdisciplinary  
Home  
Community  
Respite Care

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# The American Board of Pediatrics

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- ❑ Founded in 1933, the ABP is one of 24 certifying boards.
  - ❑ Certification by the ABP has one objective – to promote excellence in medical care.
  - ❑ ABP certification provides a standard of excellence by which the public can select pediatricians and subspecialists.
  - ❑ The Board of Directors consists of distinguished pediatricians in education, research, and clinical practice, as well as one or more non-physicians.
  - ❑ The ABP strives to improve training, establishes the requirements for certification and sets the standards for its examinations.
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# The American Board of Pediatrics Subspecialties

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- Cardiology (1961)
  - Hematology-oncology (1974)
  - Nephrology (1974)
  - Neonatal-perinatal medicine (1975)
  - Endocrinology (1978)
  - Pulmonology (1986)
  - Critical care medicine (1987)
  - Gastroenterology (1990)
  - Emergency medicine (1992)
  - Rheumatology (1992)
  - Sports medicine (1993)
  - Adolescent medicine (1994)
  - Infectious diseases (1994)
  - Medical toxicology (1994)
  - Neurodevelopmental disabilities (2001)
  - Developmental-Behavioral Ped (2002)
  - Transplant hepatology (2006)
  - Sleep Medicine (2007)
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# The American Board of Pediatrics

## Pediatric Subspecialties

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Hospital-Based	Medical	Community-Based
<ul style="list-style-type: none"> <li>▪ Neonatal-perinatal medicine (1975)</li> <li>▪ Critical care medicine (1987)</li> <li>▪ Emergency medicine (1992)</li> <li>▪ Transplant hepatology (2006)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Cardiology (1961)</li> <li>▪ Hematology-oncology (1974)</li> <li>▪ Nephrology (1974)</li> <li>▪ Endocrinology (1978)</li> <li>▪ Pulmonology (1986)</li> <li>▪ Gastroenterology (1990)</li> <li>▪ Rheumatology (1992)</li> <li>▪ Sports medicine (1993)</li> <li>▪ Adolescent medicine (1994)</li> <li>▪ Infectious diseases (1994)</li> <li>▪ Medical toxicology (1994)</li> <li>▪ Neurodevelopmental disabilities (2001)</li> <li>▪ Developmental-Behavioral Ped (2002)</li> <li>▪ Sleep Medicine (2007)</li> </ul>	<p><i>Child Abuse and Neglect (under review)</i></p> <p><i>Palliative Medicine (under review)</i></p>

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# Guidelines for Establishing a New Subspecialty

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The roles of the new subspecialists would be:

- ❑ To teach the discipline to medical students, residents, trainees in the subspecialty, and other health professionals.
  - ❑ To provide consultation in the subspecialty to general pediatricians and others.
  - ❑ To provide complex (usually tertiary) care and to perform procedures which are special to the subspecialty.
  - ❑ To create new knowledge in the field through research. There must be evidence that the new subspecialty has a unique body of knowledge and a scientific basis.
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# Guidelines for Establishing a New Subspecialty

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- ❑ The existence of a body of scientific medical knowledge underlying the area which is in large part distinct from, or more detailed than, that of other areas in which certification is offered.
  - ❑ The existence of a group of physicians concentrating their practice in the proposed area, the number of such physicians, the annual rate of increase in their number for the past decade, and their geographical distribution at present.
  - ❑ The existing national societies, the principal interest of which is in the proposed area, with an indication of the distribution of academic degrees held by their members and of the association of the membership with the specialists of medicine.
  - ❑ Numerical and geographic identification of medical school and hospital departments, divisions, or other units in which a principal educational effort is devoted to the area proposed for special certification.
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# Guidelines for Establishing a New Subspecialty

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- ❑ A statement projecting the needs for and the effect of the new certification on the existing patterns of specialty practice including but not limited to:
    - The effects of the new certification on existing practice including quality of care and the advantages to the public.
    - The effects of new certification on immediate and long-term costs and their relationship to the probable benefits.
  - ❑ There must be a sufficient number of current and potential subspecialists to justify the certification process.
  - ❑ The advantages/disadvantages of developing the certification process conjointly with other Boards with similar subspecialty interests.
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# Community Pediatrics

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An alternative to the current trajectory would be to build this new discipline on the foundation and framework of Community Pediatrics.

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Pediatrics

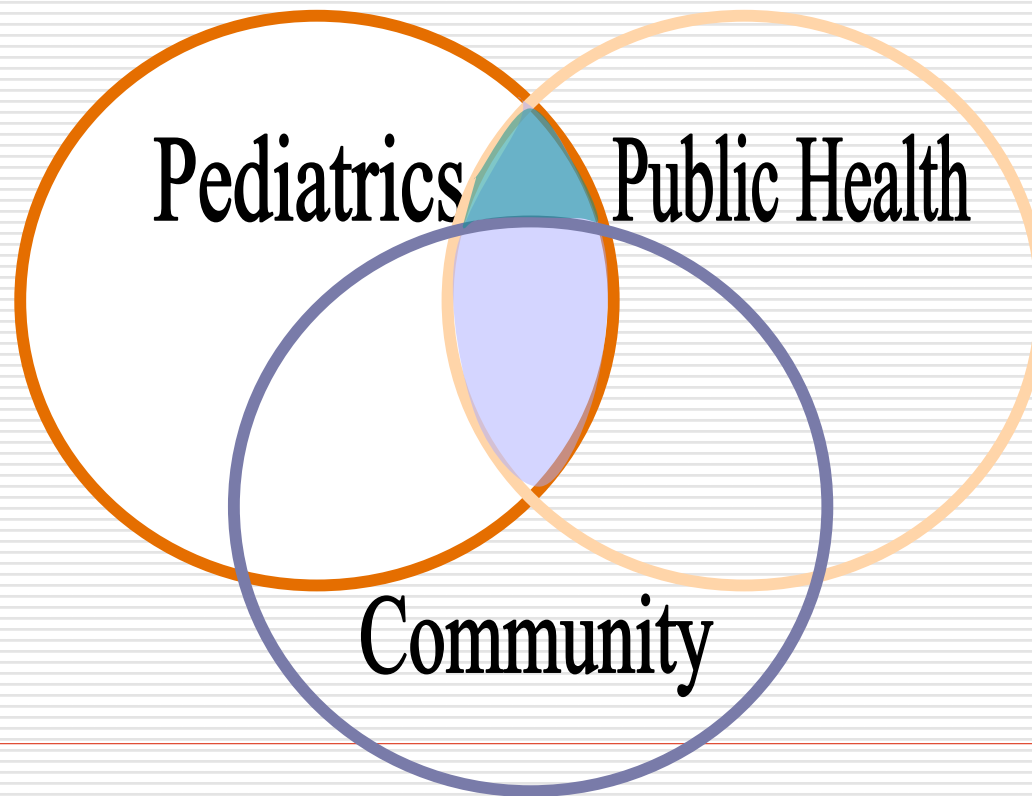
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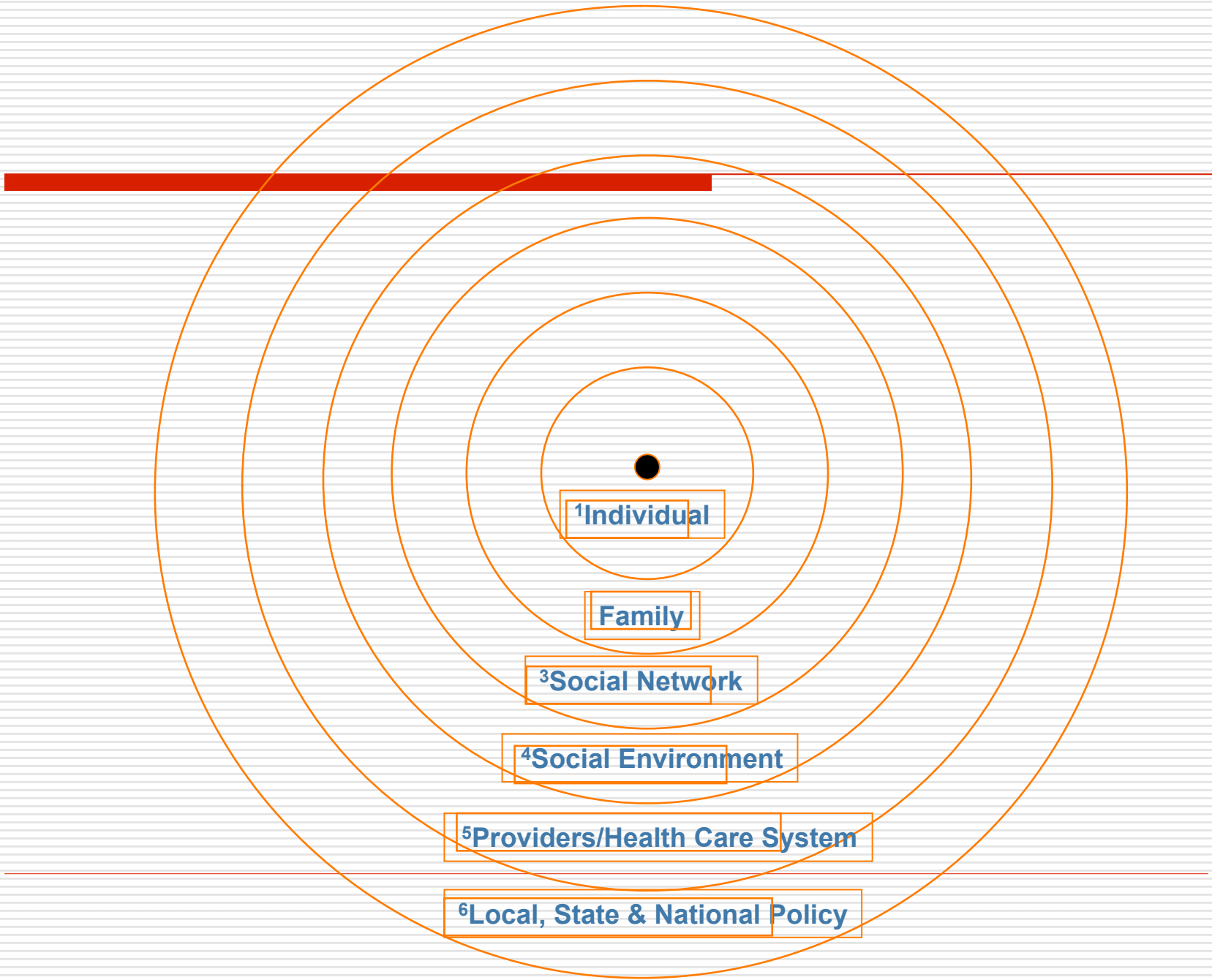
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Pediatrics Public Health

A Venn diagram consisting of two overlapping circles. The left circle is outlined in dark orange and contains the text 'Pediatrics'. The right circle is outlined in light orange and contains the text 'Public Health'. The overlapping area between the two circles is shaded in light purple. The diagram is centered on a white background with horizontal lines above and below it.

# Community Pediatrics





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Pediatrics

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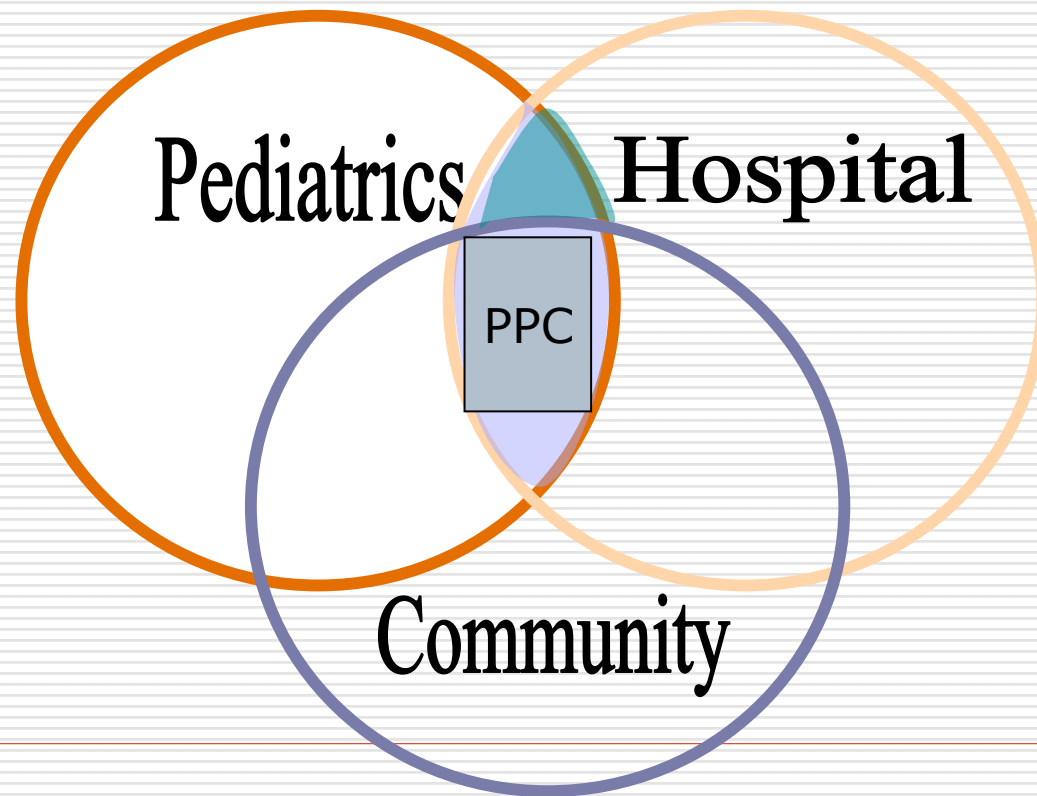


**Pediatrics** **Hospital**

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# Pediatric Palliative Care

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# AAP Community Pediatrics Policy

## 1999 and 2005

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- A perspective that enlarges the pediatrician's focus from one child to all children in the community.
  - A recognition that family, educational, social, cultural, spiritual, economic, environmental, and political forces act favorably or unfavorably, but always significantly, on the health and functioning of children.
  - A synthesis of clinical practice and public health principles directed toward providing health care to a given child and promoting the health of all children within the context of the family, school, and community.
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# Community Pediatrics Policy

## 1999 and 2005

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- A commitment to use a community's resources in collaboration with other professionals, agencies, and parents to achieve optimal accessibility, appropriateness, and quality of services for all children and to advocate especially for those who lack access to care because of social, cultural, geographic, or economic conditions or special health care needs.
  - An integral part of the professional role and duty of the pediatrician.
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# Community Pediatrics

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Community pediatrics provides a far more realistic and complete clinical picture:

- ❑ taking responsibility for all children in a community
- ❑ providing preventive and curative services
- ❑ understanding the determinants and consequences of child health and illness, and the effectiveness of services provided.

Community pediatrics is a concern for all of the population—those who remain well but need preventive services, those who have symptoms but do not receive effective care, and those who do seek medical care either in a physician's office or in a hospital

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# Conclusions

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- ❑ Argue for the development of the new discipline of Pediatric Palliative Care as a practice paradigm within the context of Community Pediatrics that integrates community and hospital-based care
  - ❑ Suggest that the current Boards in Adult Palliative Care are not relevant to the practice of Pediatric Palliative Care
  - ❑ Suggest that this new discipline be conceptualized as the synthesis of community- and hospital-based care
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# Conclusions

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- Argue against the development of a new Section in the AAP unless the Section finds its home in the Department of Community Pediatrics, linked to the Medical Home and Family Centered Care
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# **A Summative Evaluation of a Pediatric Palliative Care Program**

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# Purpose

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The purpose of this project was to evaluate the Community PedsCare pediatric palliative and hospice care program.

This evaluation was intended to provide an assessment of the impact of PedsCare palliative care services on hospital utilization and costs, and parental perceptions of health related quality of life (HRQOL).

In addition, as few previous studies have been conducted and reported, new evaluation methods and tools were to be pilot tested and evaluated.

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# Community PedsCare: Palliative Care

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- Community PedsCare was initiated in 2000
  - To address the need for holistic and coordinated care for children with chronic illnesses
  - Formed through various alliances of healthcare organizations throughout Northeast Florida, including:
    - Community Hospice of Northeast Florida
    - Baptist Health – Wolfson Children’s Hospital
    - Nemours Children’s Clinic
    - University of Florida, College of Medicine- Jacksonville
    - Jesse Ball duPont Fund
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# Community PedsCare

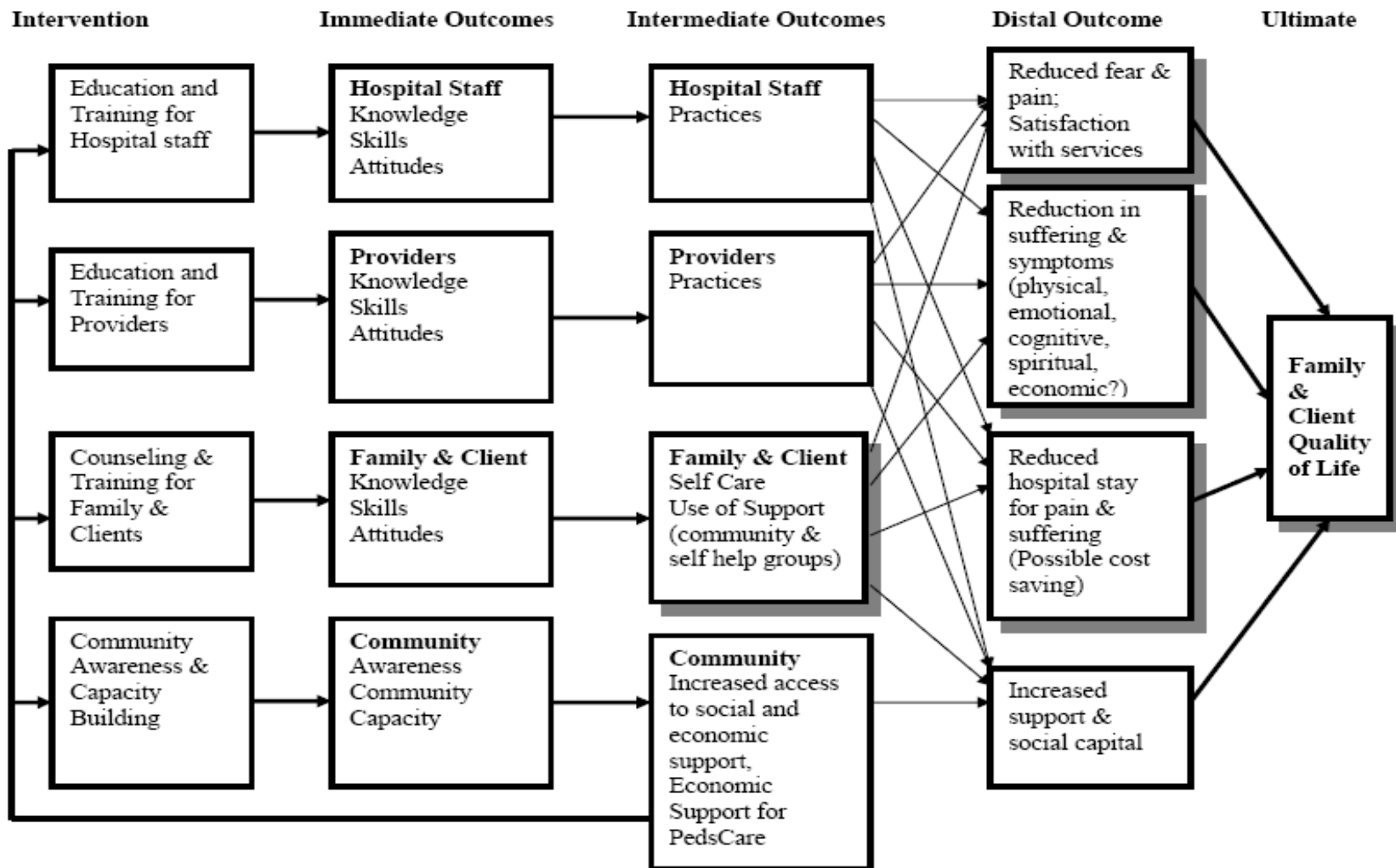
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Community PedsCare provides a multi-disciplinary team approach for children and their families with:

- home nursing assessments
  - psychosocial interventions
  - child life specialist care
  - spiritual support
  - pain and symptom management
  - volunteer interventions that complement specialized health care
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# Community PedsCare Evaluation Logic Model

Figure 1  
Evaluation Logic Model Pediatric Palliative care



# Community PedsCare Evaluation

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## Hypotheses:

- ❑ Enrollment in PedsCare will improve Quality of Life (specifically for Family Care Givers)
  - ❑ Enrollment in PedsCare will reduce hospitalization (as measured by days in hospital)
  - ❑ Enrollment in PedsCare will reduce the costs of care (particularly those associated with hospitalization)
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# Evaluation Design

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## □ Data

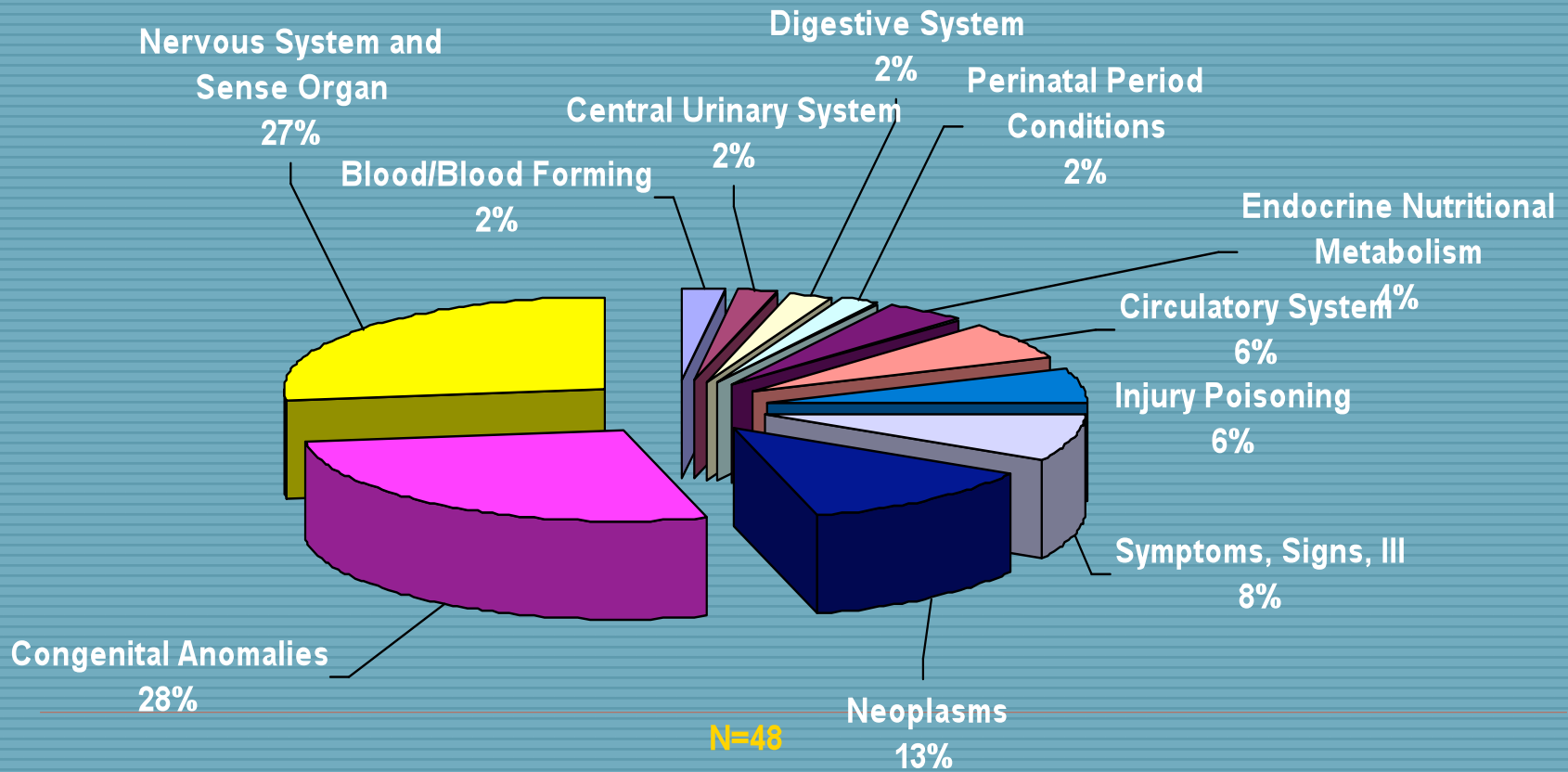
- Cost and Utilization: Secondary data hospital cost and utilization for each client
- HRQOL: Primary data collection with phone survey of family care givers

## □ Sample

- Cost & Utilization: 40 children enrolled in PedsCare over a long enough period to observe pre and post enrollment utilization and costs
  - HRQOL: 53 Family Care givers contacted by phone (76% of 70 eligible with varying periods of PedsCare enrollment)
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# Variations in Diagnostic Groups

## Diagnostic Group of Children Enrolled in Pediatric Palliative Care (Hospitalization 2000-2006)



# Results

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- ❑ There were 1,440 hospital admissions (2000 to 2006) of children with Community PedsCare represented illnesses
  - ❑ The total cost for the 1,440 hospital admissions from 2000 to 2006 was \$56,626,703.
  - ❑ There was a significant decrease ( $p = .03$ ) in hospital utilization (length of stay) for clients after enrollment into Community PedsCare, in comparison to their pre-enrollment utilization.
  - ❑ There was a promising decline in diagnostic service charges post-enrollment ( $p = .13$ ), but the overall decline in hospital charges was not statistically significant ( $p = .34$ ).
  - ❑ No significant differences were identified in service utilization and costs between PedsCare clients and non-PedsCare children with similar ICD 9 codes
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# Results

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- Family caregivers tended to score high on the HRQOL scales, but nevertheless did report a number of days of impaired functioning in the last 30 days.
- HRQOL scores for issues related to the self-efficacy of family/caregivers to care for their children tended to be higher than those that reflected the function of the health care system.
- Analysis of parental responses to the HRQOL survey revealed significant ( $p < .05$ ) and marginally significant ( $p < .20$ ) relationships to clients' length of enrollment in the Community PedsCare for the following:
  - reported days of impaired emotional health due to fear ( $p = .01$ )
  - reported days of impaired emotional health due to sadness ( $p = .16$ )
  - reported days of activity limitation due to emotional problems ( $p = .01$ )

# Hospital Days & Costs Before & After Enrollment

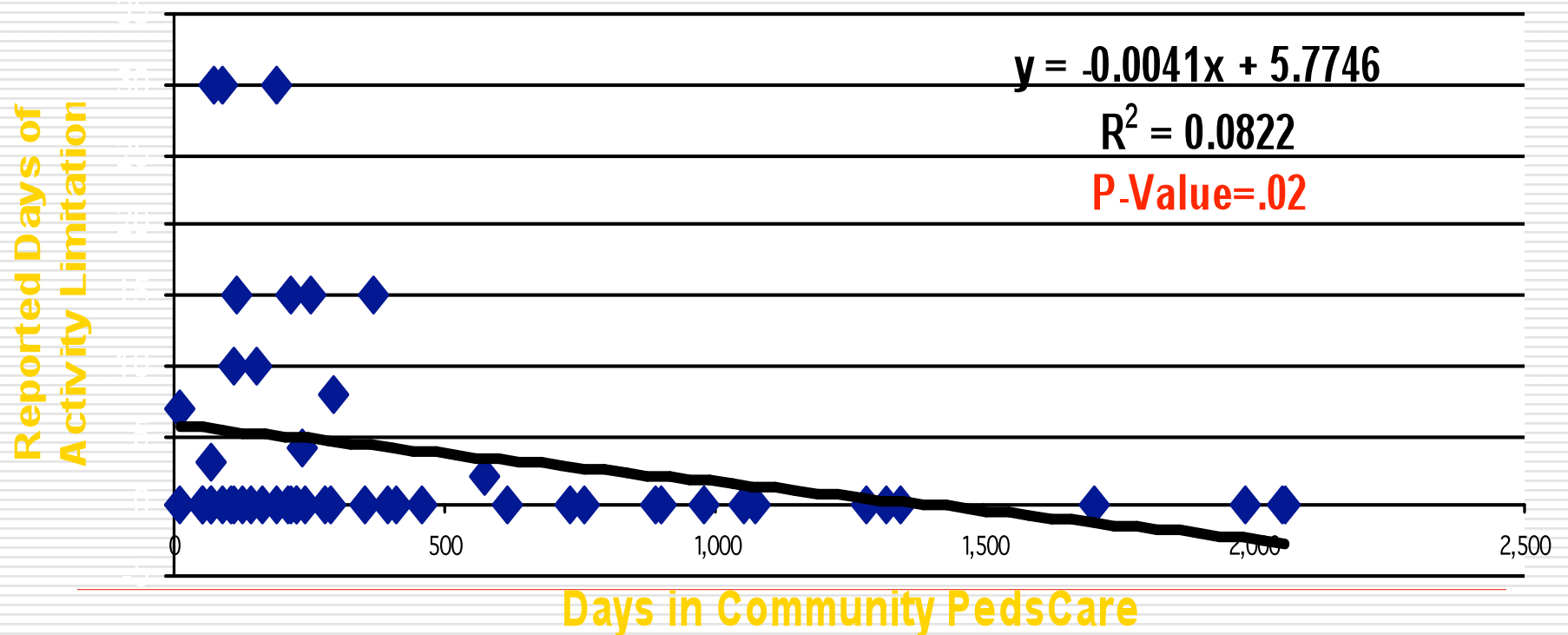
Community PedsCare Client	Before Palliative Care N=40		After Palliative Care N=40		P-value *
	Mean	Standard Error	Mean	Standard Error	
<b>Cost and Utilization Findings</b>					
<b>Hospital days (Days/Quarter)</b>	2.92	.94	1.22	.39	<b>0.03</b>
<b>Total Diagnostic Charges/Quarter</b>	\$2,125	918	\$1,078	430	0.13
<b>Total Charges/Quarter</b>	\$7,867	2,347	\$6,663	2,785	0.34

\*Paired One tailed T-test -Before and After PedsCare

Prepared by Duval County Health Department, Institute for Health, Policy, and Evaluation Research

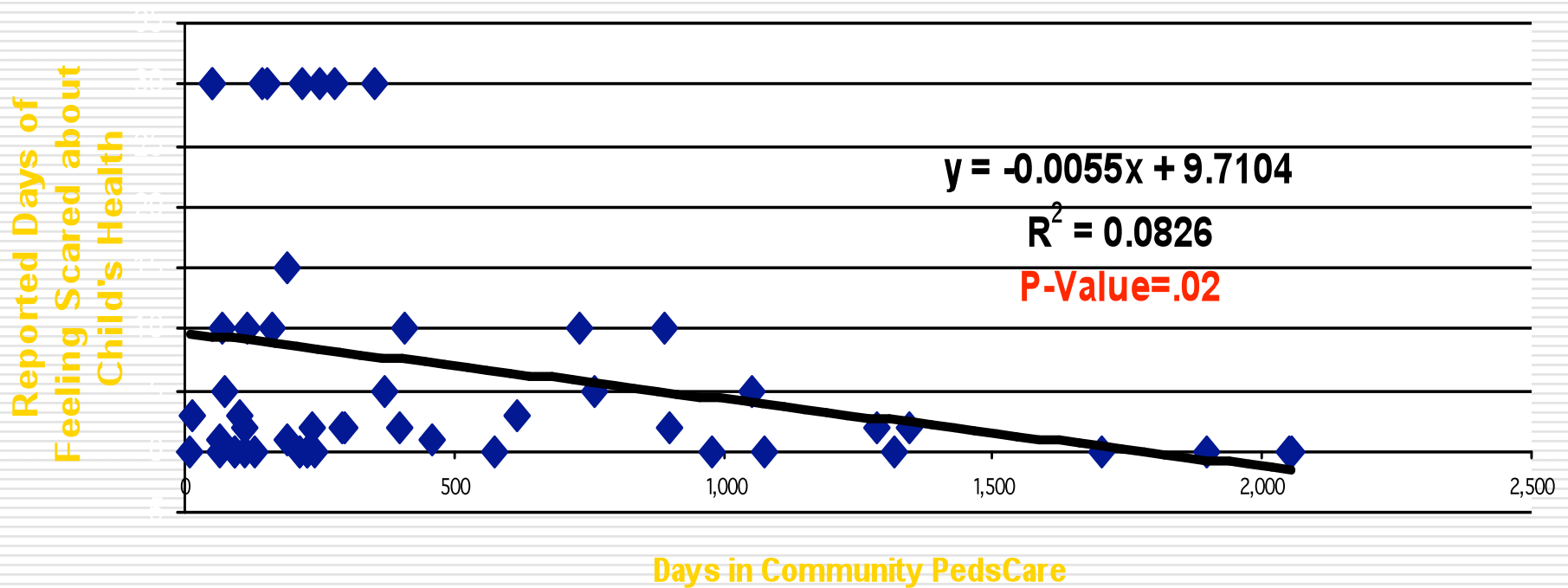
# Impact of Community PedsCare on HRQOL

Relationship of PedsCare period of enrollment to Activity Limitation due to Adverse Emotional Health



# Impact of Community PedsCare on HRQOL

Relationship of PedsCare period of Enrollment to days of feeling scared about child's health



# Limitations of Study

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- ❑ Small sample size
  - ❑ Need to factor in negative impact of disease course (degeneration of health), limiting positive impact on utilization, cost savings and health related quality of life.
  - ❑ No control group: Attempt at using control group failed; ICD 9 codes may not adequately address severity of illness, a major factor in service utilization.
  - ❑ Dose effect (the amount of time after enrollment required to produce an effect) may need to be determined before impact can be fully assessed.
  - ❑ The HRQOL survey was developed using multiple local "experts" and families, need to establish more psychometrics.
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# Conclusions

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- ❑ Results showed promising decreases in hospital costs and utilization.
  - ❑ Results showed improvements in key quality of life indicators for families with children with special health care needs.
  - ❑ Results provide important insights for program and policy development as well as evaluation research design.
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# Policy Implications

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- More studies with multiple sites are needed
  - Public and Private payers (insurers) should consider funding palliative care as an essential component of health care for children with debilitating disease.
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# Concluding Remarks: The Wizard of Oz

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Scarecrow. "I haven't got a brain,  
only straw."

Dorothy. "How can you talk if you  
haven't got a brain?"

Scarecrow. "I don't know....but some  
people without brains do  
an awful lot of talking."

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