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**DISTRICT OF COLUMBIA PEDIATRIC PALLIATIVE  
CARE COLLABORATIO: A REGIONAL APPROACH  
TO PEDIATRIC PALLIATIVE CARE**

# VISION

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The Vision of the DCPCC is to be a regionally based, nationally recognized pediatric palliative care program that promotes excellence in care for children with life limiting illnesses and their families. Through this strategic collaboration, the DCPCC capitalizes upon the strengths of academic health care institutions in DC to provide state of the art high quality palliative and hospice services to children that will become the standard for care nationwide

# MISSION

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The mission of the District of Columbia Pediatric Palliative Care Collaboration is to provide a health care delivery system which provides optimal care to children with life-threatening illnesses and their families in the District of Columbia across the spectrum of care settings from inpatient to home-based. In support of this mission, the DCPCC is committed to professional and public education, advocacy for this population, and research that will develop the standards of state-of-the-art palliative care for children

# OBJECTIVES

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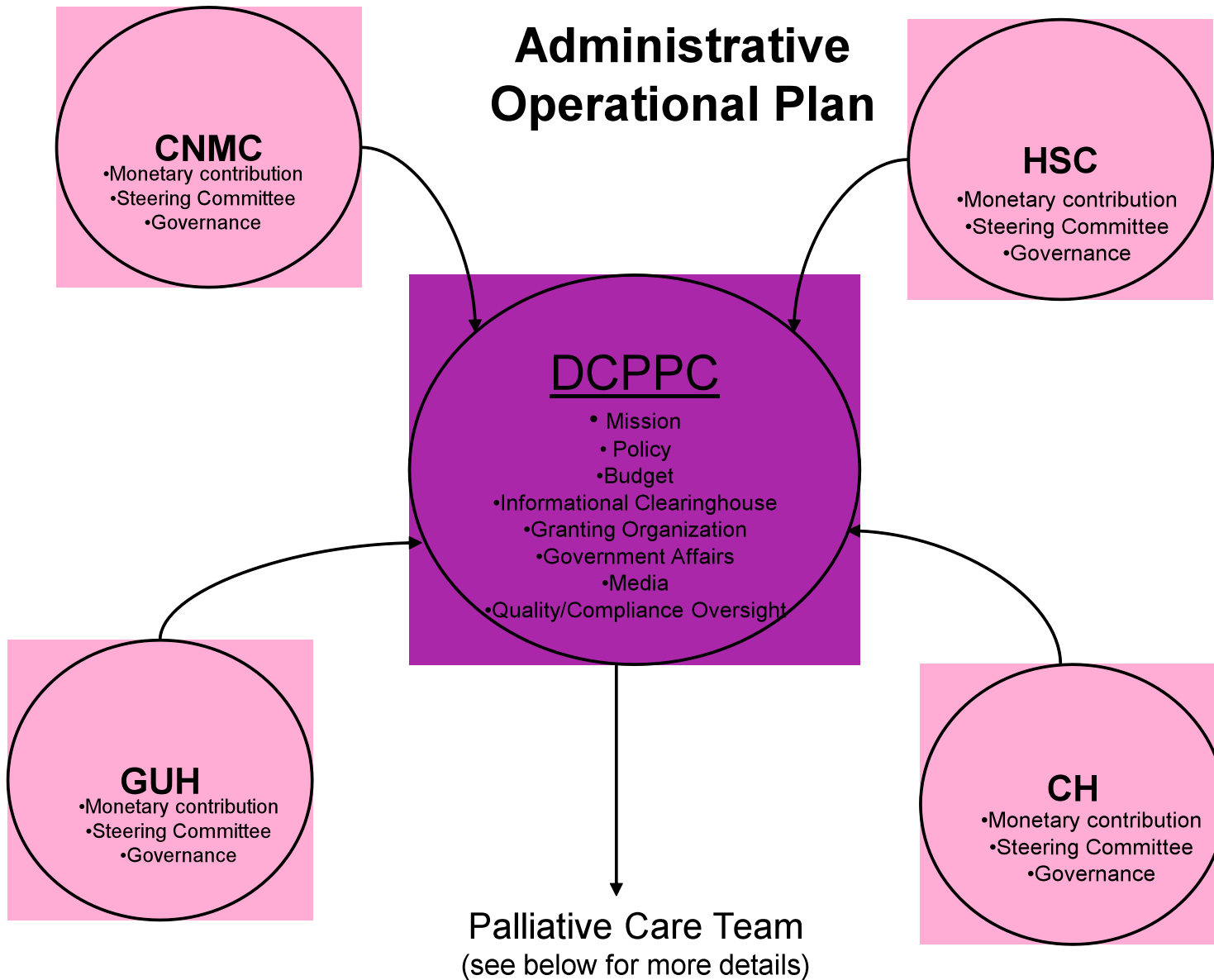
- ✘ Provide comprehensive palliative and hospice care for children, and their families, in the District who are facing life-threatening illnesses;
- ✘ Provide these services wherever they most meet the needs of these children and their families, including hospitals, ambulatory clinics, respite facilities, and in their homes;
- ✘ Develop best practices and standards of care;
- ✘ Educate health care professionals, students and the public – including governmental leaders – about the need for these services throughout the country

## OBJECTIVES (CONT'D)

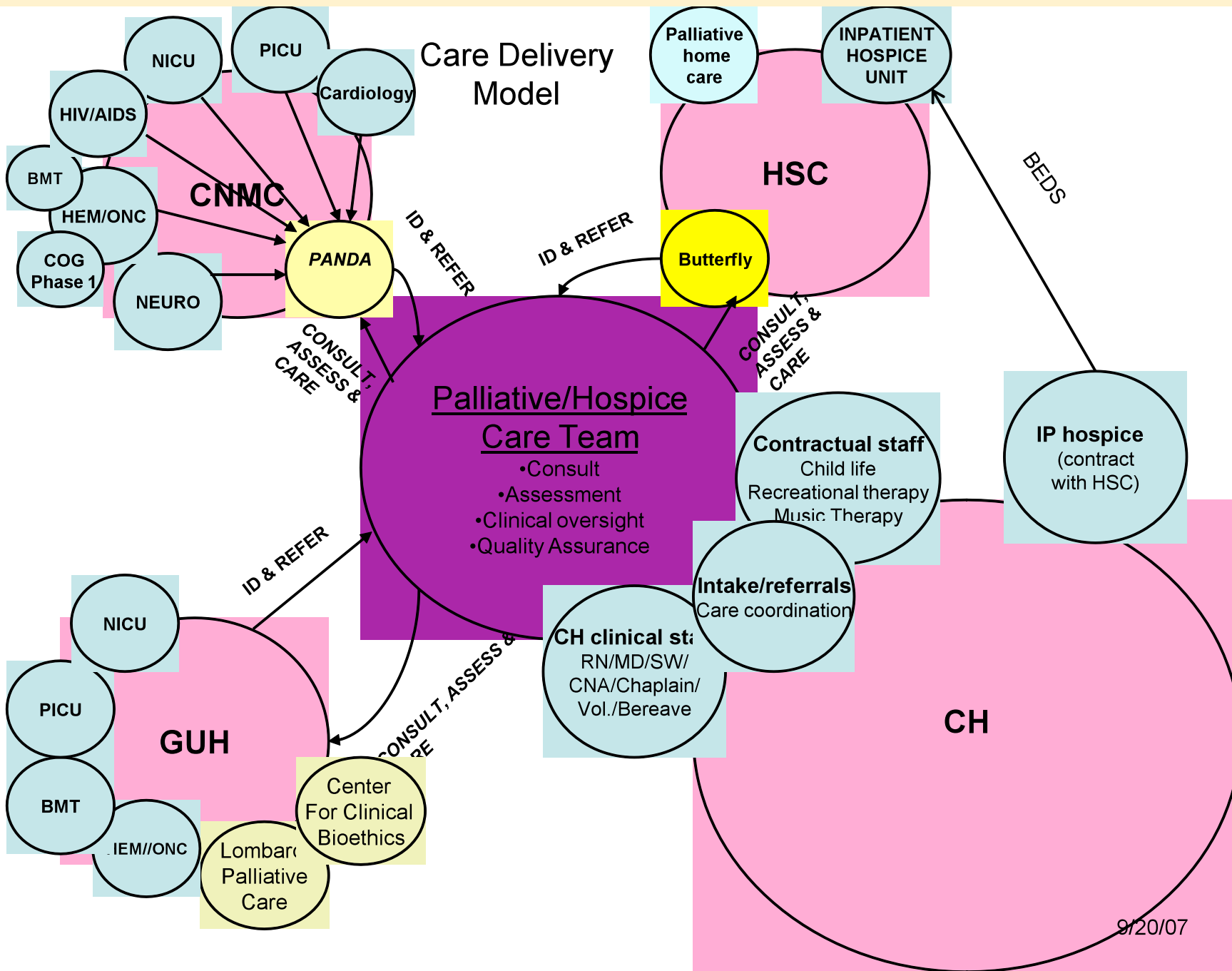
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- ✘ Provide the rest of the United States with a model of care for children that takes advantage of the resources of the entire community, including research and teaching hospitals, universities, and community based service organizations;
- ✘ Become financially self-sustaining within three years of inception

# Administrative Operational Plan



8/16/2007



# BARRIERS TO PEDIATRIC PALLIATIVE CARE

- ✘ Education
- ✘ Funding
  - + Lack of prime payor source
  - + Waiver issues with CMS and local governments
- ✘ Public and professional awareness
- ✘ Current models based on adult patient experience, e.g., caseloads for hospice nurses with pediatrics

# NEEDS ASSESSMENTS

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- ✘ Organizational
- ✘ Unit
- ✘ Staff
  - IRB submission
- ✘ Patient and Family
  - IRB submission

# COMMUNITY RESOURCE GUIDE

- ✘ *HSC Foundation's Community Resource Guide for Children*
  - *English and Spanish versions*
  - *Pediatric Palliative Care Section Supplement*
- ✘ *Template for Parent Booklet*
- ✘ *Template for Child's Booklet*

# EDUCATION PLAN FOR CLINICAL STAFF

## ✘ Assessment Phase

→ Administer validated pre-tests

- ◇ Unipac Pediatric Pretest Tool
- ◇ Aspects of Growth and Development
- ◇ Developmental Aspects of Pain Management

# EDUCATION PLAN (CONT'D)

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## ✘ Curriculum Phase

- + Pre- and post-test findings guide education plan
- + Needs assessments guide areas needing special focus (e.g., growth and development)
- + Modified UNIPAC, Pediatric ELNEC, IPPC
- + Current literature on state-of-the-art

# CONTINUING EDUCATION

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- In-services for staff *and* referring clinicians
- Annual Conference
- Pediatric Palliative Care Grand Rounds (quarterly)
- Pediatric Palliative Care Journal Club (monthly)

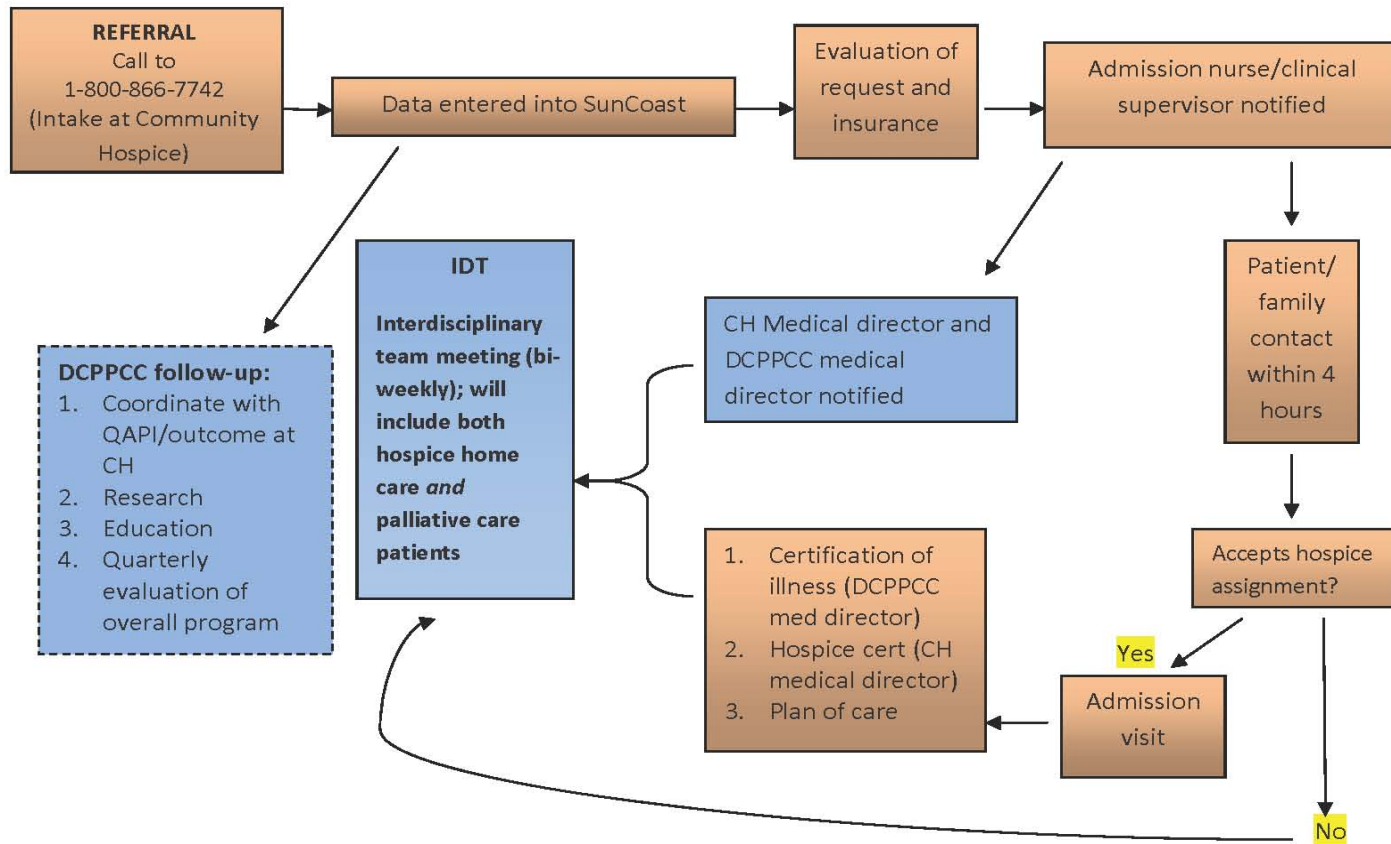
# MODELS OF CARE

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1. Early identification and referral (e.g., at time of diagnosis)
2. Central intake and referral number
3. Standardization of best practices in symptom management, psycho-social support, and bereavement
4. **Continuity of care:** a seamless transition between facilities and homes; coordination of services; avoidance of multiple new providers

## Referral process for all patients

### Process Overview



#### Notes:

- All referrals **must** go through the 1-800-866-7742 number at Community Hospice
- Boxes shaded in peach represent processes developed and managed by Community Hospice
- Boxes shaded in blue represent collaborative or shared processes
- The disposition of children referred via the 1-800, *but who are not eligible or who do not choose home hospice*, remains open

# DATA BASE

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- ✘ One central repository for *all* referrals, irrespective of whether the referral becomes hospice, palliative care, or on-going psycho-social support
- ✘ Provides:
  - + Real-time assessment of symptom management (scores)
  - + Regular review
  - + Demographic and epidemiologic data

# QUALITY OUTCOMES

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- ✘ Clinical

- + Pain and symptom management scores
- + Psychosocial, bereavement
- + Satisfaction scores (patients and caregivers)

- ✘ Education – outcomes of conferences, in-services

- ✘ Service delivery:

- + Satisfaction scores (referring clinicians)
- + Satisfaction scores (staff)

# FINANCIAL PLAN

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- ✘ DCCC – start-up funds for 2007 and 2008
- ✘ Institutional Support – each of the four member organizations contributes quarterly to the project
- ✘ Appropriations – applying for 2009 to both federal and local governments
- ✘ Grants
- ✘ Fundraising
- ✘ Waiver 1915c – submitted to the District DOH

# STANDARDS AND BEST PRACTICES

- ✘ Absence of consensus on best practices
- ✘ Most hospice/palliative research is in adults
- ✘ Solutions:
  - + Standardization: of medications, routes of administration, etc.
  - + Measurement of outcomes: PAIN scores that are developmentally appropriate

# FUTURE PLANS

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- ✘ Palliative consult service
- ✘ Inpatient palliative/respite
- ✘ Palliative care clinics
- ✘ Fellowships (for *all* disciplines)
- ✘ Simulator training