

Pittsburgh Pediatric Palliative Care Coalition RESOURCE MAP

INFORMATION

ALLEGHENY COUNTY
RESPITE CARE
COALITION

SPECIAL KIDS NETWORK

HELPING HANDS
HEALING HEARTS

CASE MANAGEMENT

CHILDREN'S HOSPITAL
SUPPORTIVE CARE
PROGRAM

HIGHMARK CARING
PROGRAM FOR CHILDREN
WITH SPECIAL NEEDS
(PLANNED)

MH/MR & MEDICAID
PROVIDERS

HOME HEALTH PROGRAMS (sampling)

CARE UNLIMITED

EXTENDED FAMILY CARE

INTERIM HEALTHCARE

MEDICAL SUPPORT

ALLEGHENY GENERAL
HOSPITAL

THE CHILDREN'S HOME -
TRANSITIONAL INFANT
CARE

CHILDREN'S HOSPITAL

CHILDREN'S HOSPITAL &
VENTILATOR HOME
PROGRAM

CHILDRENS HOSPITAL
SUPPORTIVE CARE
PROGRAM

CHILDREN'S INSTITUTE

WEST PENN HOSPITAL

EDUCATION

CHILDREN'S INSTITUTE

WESTERN PA SCHOOL
FOR BLIND CHILDREN

EDUCATION LAW
PROJECT

RESPITE

ACHIEVA

CENTER FOR CREATIVE
PLAY

CHILDREN'S HOME
(PLANNED - 2007)

CHILDREN'S INSTITUTE
(PLANNED 2006)

MC GUIRE HOME

THE WATSON INSTITUTE
CARE BREAK

WESTERN PA SCHOOL
FOR BLIND CHILDREN
(for students)

RONALD MC DONALD
HOUSE

CENTER FOR
CREATIVE PLAY

HOSPICE

FAMILY HOSPICE AND
PALLIATIVE CARE

FORBES HOSPICE

CARE UNLIMITED'S
HOPE HOSPICE

THREE RIVERS
HOSPICE

END OF LIFE

INSTITUTE TO ENHANCE
PALLIATIVE CARE

TAKE CHARGE
PARTNERSHIP

OTHER RESOURCES

CHILD'S WAY - THE
CHILDREN'S HOME OF
PITTSBURGH

EVERY CHILD, INC

CONGREGATIONS/
SPIRITUAL SUPPORT

MAKE-A-WISH
FOUNDATION

UCP OF PITTSBURGH

FUNERAL
DIRECTORS

BEREAVEMENT

CANDLELIGHTERS

CENTER FOR TRAUMATIC
STRESS IN CHILDREN &
ADOLESCENTS
@ ALLEGHENY GENERAL
HOSPITAL

COMPASSIONATE FRIENDS

GOOD GRIEF CENTER FOR
BEREAVEMENT SUPPORT

HIGHMARK CARING PLACE

SIDS OF PA

LEGAL RESOURCES:
DISABILITY LAW
PROJECT; LAWYERS

MH/MR PROVIDERS

INFORMATION

SERVICE PROVIDED

CURRENT GAPS

ANTICIPATED GAPS

ALLEGHENY COUNTY
RESPITE CARE
COALITION

Provides information about providers and payment sources to families and caregivers in need of respite throughout their lifespan. Maintains list of respite care providers. Raises money to help families pay for respite care

SPECIAL KIDS NETWORK

Provides information to families with special needs kids.

HELPING HANDS
HEALING HEARTS

1. Education: workshops to families and professionals
2. Information. Family referral guide; family web resource guide
3. Volunteer. Currently developing a program to channel volunteers to existing palliative care programs.

No paid staff for two of the organizations. Special Kids Network is statewide and too broad of a service to offer specific referrals to families. Many other organizations provide information, but it is not their core mission.

No centralized place for families to receive information.

CASE MANAGEMENT

CHILDREN'S HOSPITAL
SUPPORTIVE CARE
PROGRAM

Multidisciplinary team provides palliative care throughout child's life-both in and out of the hospital.

1. Help parents make decisions
2. Support patients and families through illness, recovery or bereavement.
3. Ensure comfort
4. Address holistic needs of child-referrals to appropriate supports.

Provides training in Pediatric palliative care - over 500 trained. Served 82 families last year for an average of 48 days. Serving 40- 50 families at one time. Growing rapidly. New program; available to any child with a life-threatening illness.

No individualized, comprehensive case management service that addresses the full spectrum of a family's needs.

Comprehensive case management services available to all families with medically fragile children.

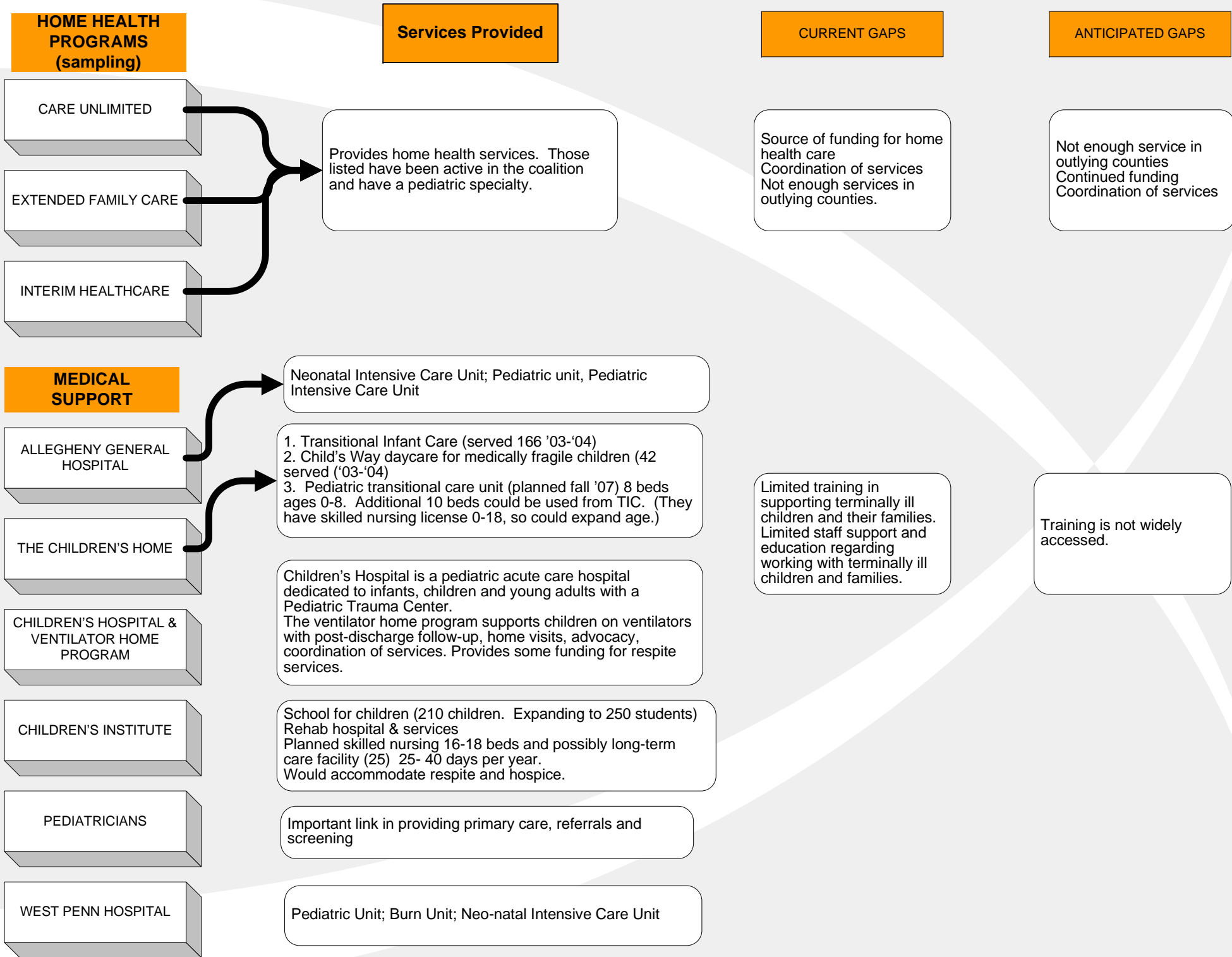
HIGHMARK CARING
PROGRAM FOR CHILDREN
WITH SPECIAL NEEDS
(PLANNED)

Coordination of services for families. Provide education and resource information to families, physicians, and community organizations. Advocate for children and families Available to special needs children insured by Highmark.

MH/MR CASE MANAGERS

Provide agency related case management services to their clients.

MEDICAID CASE
MANAGERS



RESPITE

Services Provided

CURRENT GAPS

ANTICIPATED GAPS

ACHIEVA

Provides respite services for special needs children. Fee for service paid by MR waiver. Some by Gateway insurance (home health, not respite). Private pay available

Overnight respite facility primarily for MR at Emmaus Center South Hills. 5 bedroom unit. Accepts some medically fragile with fee for service.

CENTER FOR CREATIVE PLAY

Provides a place for special needs children and their families to play together. Provides weekly respite program (Our Time) for special needs children (12-5 on Saturdays) as fee for service program.

CHILDREN'S HOME
(PLANNED - 2007)

Pediatric Transitional Unit (planned '07) Could be used for respite or transitional care. 8 beds (10 additional TIC available if overflow needed) Ages 0 - 8

CHILDREN'S INSTITUTE
(PLANNED 2006)

Planned skilled nursing 16-18 beds available for respite 25-40 days per year. Possibly long-term care facility (25 beds) Would accommodate hospice. Would hire new staff.

MC GUIRE HOME

31 days a year limit. MR only. Don't accept technology dependent children. 4 beds (2 taken by long-term emergencies usually)

THE WATSON INSTITUTE
CARE BREAK

Provides respite care for children by pairing volunteers with families. 2-4 hours a week in one visit/ weekly. Children 0 - 16 with Physical disabilities, mental retardation, autism and other disabilities. Can accept children with feeding tubes and adaptive equipment. 18 - 20 volunteers placed annually. 60 - 80 children served/ year.

WESTERN PA SCHOOL
FOR BLIND CHILDREN

5 days (overnights) per year (not June 11 - July 18; August) available to day students. Handle technologically fragile. 17 children used service in '03-04. 1 bed available

Funding is extremely limited for non-MR children.

Daytime:

- Few out of home services available.

Overnight respite:

- Currently only available for MR diagnosis and for students of W.PA School for Blind Children.

Overnight:
No payer source for overnight respite.
No home-like setting.

Daytime:
No change—still limited.
Limited by funds available

HOSPICE

SERVICES PROVIDED

CURRENT GAPS

ANTICIPATED GAPS

FAMILY HOSPICE AND
PALLIATIVE CARE

Karing for Kids program provides hospice & palliative care for children.
Partners with UPMC and the Institute to Enhance Palliative Care
Served 6-7 children in the last 5 years.
Acquired building for in-patient hospice. One room will be developed for pediatric patients. ('06) Most would be in-home. Plan to increase pediatric. Pro-bono cases accepted.

FORBES HOSPICE

Provides Hospice and palliative care to children. Served 20 children (and 1000 adults) in 2004
12 beds plus in home care. Trained volunteers
Puppetry, music, pet therapy, massage, giving library. Has a designated pediatric division.

CARE UNLIMITED'S
HOPE HOSPICE

Hospice component of Care Unlimited Home Health.
"Handful" of children received hospice. Training program for employees on end of life issues for children.

THREE RIVERS
HOSPICE

Provides pediatric hospice and through their home health division, also provide home health & palliative care.
Served 16 children in '04. Have about 4-6 children at a time. Have capacity to serve more, but have not had more referrals. Developed a fund 1 ½ years ago to cover non-reimbursable pediatric expenses

END OF LIFE

TAKE CHARGE
PARTNERSHIP

Provide training and online resources about end-of-life issues and decision-making with consumers, professionals, community organizations and corporations.

INSTITUTE TO ENHANCE
PALLIATIVE CARE

Research, Education & Training and Community Education & Advocacy.
The Coalition for Quality at the End of Life (CQEL):
1. System Capacity Building-professionals & providers aim at changing systems.
2. Financing & Policy: Working to break down regulatory & financing barriers
3. Community Engagement. Raise community awareness & build consumer involvement
4. Measurement: articulate plans & evaluation of effectiveness.

Limited # of children served.
No pediatric specific hospice. Only one has a specifically designated pediatric nurse.
No beds specifically for pediatric in-patient hospice.
Funding is on a per-diem basis and doesn't cover all costs. Generally not covered simultaneously with in home skilled/shift nursing.
Limited Hospice-based bereavement services specific to parents, siblings and family members.
No respite services for pediatric patients.

Beds only available in an adult patient hospice setting.

No community based anticipatory grief counseling.
No independent end-of-life decision making counseling.

No community based anticipatory grief counseling.
No independent end-of-life decision making counseling.

BEREAVEMENT

Services Provided

CURRENT GAPS

ANTICIPATED GAPS

CANDLELIGHTERS

Provides family support for families of children diagnosed with cancer.
Provides information, emotional support and financial support. Provides activities, newsletter and is affiliated with the national office.

CENTER FOR TRAUMATIC
STRESS IN CHILDREN &
ADOLESCENTS
@ ALLEGHENY GENERAL HOSPITAL

Provide counseling and treatment for children experiencing post traumatic stress.

COMPASSIONATE FRIENDS

Self-help support group for bereaved parents, grandparents and siblings. Meet monthly.

GOOD GRIEF CENTER FOR
BEREAVEMENT SUPPORT

One on one peer support for anticipatory and post-death grief
Referrals to bereavement support groups (List of 146 support groups or organizations)
Lending Library of books on grief & loss
Workshops & seminars for professionals and family members.
Memory Garden

HIGHMARK CARING PLACE

Support groups for grieving children and their families who have lost a parent or sibling.
10 - 12 sessions. (10 groups throughout year) 17- 20 families each group.
¼ of families sibling or grandparent died

SIDS OF PA

Support group for families who have lost a child for any reason. Also raises awareness about SIDS.

Limited awareness of community bereavement support
No community based anticipatory grief counseling
Limited sibling support

Same

OTHER RESOURCES

Services Provided

CURRENT GAPS

ANTICIPATED GAPS

CONGREGATIONS/
SPIRITUAL SUPPORT

Provide spiritual and community support

EVERY CHILD, INC

Provide family support and wrap-around services for families with medically fragile children who are at risk of living outside of their family. Also work to seek adoptive families for medically fragile children awaiting placement.

CENTER FOR CREATIVE
PLAY

Provides a place for special needs children and their families to play together. Provides weekly respite program (Our Time) for special needs children (12-5 on Saturdays) as fee for service program.

FUNERAL DIRECTORS

Provide emotional support and are often a referral source for bereavement care.

MAKE-A-WISH
FOUNDATION

Provides wishes to children who are living with a life threatening medical condition and are between the ages 2 ½ and 18. Granted 541 wishes in 2004 in whole region

MENTAL RETARDATION
PROVIDERS

Provide support to medically fragile children with MR needs.

LEGAL RESOURCES:
DISABILITY LAW
PROJECT

Provides system wide advocacy and legal services to people with disabilities.

RONALD MC DONALD
HOUSE

Provide living accommodations to out of town families as their child receives treatment at Pittsburgh medical facilities.

UCP OF PITTSBURGH

Provide recreational activities through their children's program.

Families mentioned the need for more recreational activities, housing modification, financial assistance, transportation, lending program for adaptive equipment, and long-term planning.

Same