

Debra Chopp
Clinical Asst. Professor of Law
Pediatric Advocacy Director
734.763.1948

Kimara Thompson
Administrator/
Legal Assistant
734.763.1945

UNIVERSITY OF MICHIGAN LAW SCHOOL
PEDIATRIC ADVOCACY CLINIC

2076 South Hall
701 S. State Street
Ann Arbor, MI 48109-3091
Tele: 734.763.1942 • Fax: 734.764.8242

L. Kate Mitchell
Clinical Fellow
734.763.1947

Student Attorney Line
734.763.1942

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This report, prepared by the University of Michigan Law School Pediatric Advocacy Clinic¹, is a work in progress. We welcome any suggestions and input.

The Pediatric Advocacy Clinic is a pediatric medical-legal partnership² which strives to improve the health and well-being of children through the infusion of legal services into the health care setting. The PAC receives case referrals from medical partners and focuses on cases that improve the health and well-being of children in poverty. The PAC primarily represents families with children with chronic medical conditions and disabilities in a variety of civil matters including special education, access to health care and public benefits, housing, and family law. The PAC also seeks to collaborate with pediatric medical providers to work towards systemic change to improve services and systems serving children with disabilities and children in poverty.

We were asked to provide information regarding the variations in the provision of hospice, palliative care, and concurrent care services to terminally ill children throughout the United States. In preparing this report, we were researching the following issues:

1. Medicaid waivers affecting pediatric care, especially pediatric palliative care
2. Whether any states have enacted or are in the process of enacting:
 - a. Legislation affecting pediatric palliative care;
 - b. Legislation that gives a more precise definition of pediatric palliative care in order to achieve the same reimbursement as is available for hospice;
 - c. Legislation that widens access to Medicaid;
 - d. Legislation that expands the 6-month life expectancy requirement for access to hospice.

¹ For more information on the Pediatric Advocacy Clinic, please visit our website:
<https://www.law.umich.edu/clinical/pediatricadvocacyclinic/Pages/default.aspx>

² For more information about medical-legal partnerships and the MLP movement, visit the website for the National Center for Medical-Legal Partnership: <http://medical-legalpartnership.org/>

Introduction to Pediatric Palliative Care Under the ACA

- **Institute for Innovation** Pediatric Concurrent Care guide:
http://www.nhpco.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf
 - - o “[The ACA] requires all state Medicaid programs to pay for both curative and hospice services for children under age 21 who qualify. On March 23, 2010, President Obama signed ACA into law enacting a new provision, Section 2302, termed the “Concurrent Care for Children” Requirement (CCCR). Section 2302 states that a child who is eligible for and receives hospice care must also have all other services provided, or have payment made for, services that are related to the treatment of the child’s condition. This provision affects children who are eligible for Medicaid or the Children’s Health Insurance Program (CHIP). In its simplest form, implementation of this provision could be accomplished by the state Medicaid agency eliminating any provider claims that deny or delay concurrent curative care and hospice claims.”
 - “Hospice care” means a doctor must say a child is within 6 months of end of life or else this section doesn’t apply.
 - If a state’s Medicaid program doesn’t cover the required care, then this section doesn’t apply.
 - “While Section 2302 is a positive step forward in obtaining better care for children at the end of life, it does not expand the types of services that are available, nor does it provide palliative care or other supportive services to children with life-limiting or life-threatening conditions whose prognosis falls outside the last six months of life should the disease or condition follow its normal course.”
 - Provider Questions and Answers from CMS about § 2302 (Feb. 8, 2011)
http://www.nhpco.org/sites/default/files/public/ChiPPS/Children_QA_%20CMS_Feb2011.pdf
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<i>Medicaid Waivers and similar legislation</i>	-	<i>Pages 3 – 6</i>
<i>Expansion of Hospice Definitions</i>	-	<i>Page 7</i>
<i>Focus on Increased Access and Awareness of Palliative Care</i>	-	<i>Page 8</i>
<i>Legislation still in process</i>	-	<i>Page 9</i>
<i>Failed Legislation</i>	-	<i>Page 9</i>
<i>State Advocacy Groups, Coalitions, Respite Homes</i>	-	<i>Page 10</i>
<i>Other Resources</i>	-	<i>Page 10</i>

Medicaid Waivers and Other Similar Legislation

- **Alaska** 1915(c) Waiver: AK Children with Complex Medical Conditions (0263.R04.00)
 - o Children (0-21 years old) who have a severe chronic physical condition and who would receive long-term care in a facility for more than 30 days per year, who have a severe chronic physical condition which results in a prolonged dependency on medical care or technology to maintain health and well-being and who:
 - Experience periods of acute exacerbation or life-threatening conditions,
 - Need extraordinary supervision and observation, and
 - Need frequent or life-saving administration of specialized treatments, or dependency on mechanical support devices.
- **California** 1915(c) waiver: CA Nursing Facility/Acute Hospital Waiver (0139.R04.00)
 - o Provides case management/coordination, habilitation, home respite, waiver personal care services, community transition, continuous nursing and supportive services, environmental accessibility adaptations, facility respite, family/caregiver training, medical equipment operating expense, PERS-installation and testing, PERS, private duty nursing including home health and shared services, transitional case management
 - o For medically fragile and technology dependent individuals
 - o Age 0 and up, no maximum age
- **California** 1915(c) waiver: CA Pediatric Palliative Care (0486.R01.00)
 - o Provides care coordination, home respite care, personal care, expressive therapies, family counseling, family training, out of home respite care, pain and symptom management
 - o For medically fragile and technology dependent individuals
 - o Ages 0-20
- **California** 1915(c) waiver: CA In Home Operations (0457.R01.00)
 - o Provides case management/coordination, habilitation services, home respite, waiver personal care, community transition, environmental accessibility adaptations, facility respite, family training, medical equipment operating expense, PERS-installation and testing, PERS, private duty nursing-including shared services, transitional case management
 - o For medically fragile and technology dependent individuals
 - o Ages 0 and up, no maximum age
- **California:** Medi-Cal Pediatric Palliative Care Benefit program, implemented in select counties throughout California, enables children to receive palliative (comfort) care in their home in addition to the treatment they receive at the hospital. Thanks to this program, families on public insurance are no longer forced to make a heart-wrenching decision between easing their children's suffering or receiving treatment that could cure their children's illness or prolong their lives. (CA Code 14132.74)
 - o Services covered under the pediatric palliative care benefit shall be designed to meet the unique needs of children, and shall include those types of services that are available through the Medi-Cal hospice benefit.
 - o Defines palliative care: **"Palliative care"** means interventions that focus primarily on reduction or abatement of pain and other disease-related symptoms, rather than treatment aimed at investigation and intervention for the purpose of cure or prolongation of life." CA Health and Safety Code Division 2 Chapter 2 Article 10.5 1339.31
- **Colorado** 1915(c) waiver: CO Children's HCBS (4157.R05.00)
 - o Provides case management and in home support
 - o For medically fragile individuals
 - o Ages 0-17
- **Colorado** 1915(c) waiver: CO HCBS – Children's Habilitation Residential Program (0305.R04.00)
 - o Provide habilitation, respite, behavioral assessment, behavioral services, professional services, and supported community connections
 - o For individuals with developmental disability
 - o Ages 0-20

- **Colorado** 1915(c) waiver: CO Children’s Extensive Support (4180.R04.00)
 - o Provides homemaker, personal care, respite, vision, adapted therapeutic recreational equipment and fees, assistive technology, behavioral services, community connector, consumer directed attendant support, home accessibility adaptations, parent education, professional services, specialized medical equipment and supplies, vehicle modifications
 - o For individuals with developmental disability
 - o Ages 0-17
- **Colorado** 1915(c) waiver: CO Children with Life Limiting Illness (0450.R01.00)
 - o Provides respite care, bereavement counseling, expressive therapy, massage therapy, palliative/supportive care services provided concurrently w/curative care services
 - o For medically fragile individuals
 - o Ages 0-18
- **Connecticut** 1915(c) waiver: CT Katie Beckett (4110.R06.00)
 - o Provide case management
 - o For people with physical disabilities
 - o Ages 0-22
- **Florida** 1915(c) waiver: FL Model Waiver (40166.R04.00)
 - o Provides respite, transition case management, assistive technology and service evaluation, environmental accessibility adaptations
 - o For medically fragile individuals
 - o Ages 0-20
- **Illinois** 1915(c) waiver: IL HCBS Waiver for Children that are Medically Fragile, Technology Dependent (0278.R03.00)
 - o Provides respite, environmental accessibility adaptations, family training, medically supervised day care, nurse training, placement maintenance counseling, specialized medical equipment and supplies
 - o For medically fragile and technology-dependent individuals
 - o Ages 0-20
- **Maryland** 1915(c) waiver: MD Model Waiver for Medically Fragile Children (40118.R06.00)
 - o Provides case management, certified nursing assistant, medical day care, principal physician's participation in the plan of care meeting, private duty nursing
 - o For medically fragile individuals
 - o Ages 0 and up, no maximum age
- **Massachusetts:** An Act Providing Access to Affordable, Quality, Accountable Health Care
 - o Legislation that created state-funded health care system and opted out of federal subsidy in 2006. Led to establishment of the Pediatric Palliative Care Network program. Expanded healthcare coverage to 300% of poverty and included an individual mandate. Amended to be consistent with the ACA. <https://malegislature.gov/Laws/SessionLaws/Acts/2006/Chapter58>
- **Michigan** 1915(c) waiver: Children's Waiver Program
 - o Ages 0-21
 - o Aimed at mental or developmental disability; provides respite, child therapeutic foster care, community living supports, community transition, family home care training, family support and training, home care training-non-family, therapeutic activities, therapeutic overnight camping, wraparound for individuals with mental illness SED
- **Michigan** Children’s Special Health Care Services http://www.michigan.gov/mdhhs/0,5885,7-339-71547_35698---,00.html
- **Nevada** 1915(c) waiver: HCBW for Persons w/ID and Related Conditions 0125.R06.00
 - o Individuals with ID ages 0-no max; Provides day hab, prevocational, residential support, supported employment, behavioral consultation-training & intervention, counseling, career planning, non-medical transportation, nursing, nutrition counseling, residential support management

- **New York** 1915(c) waiver for medically fragile children: “Care at Home” program
 - o Ages birth-17; children who are determined to be physically disabled based on SSI criteria and who would otherwise require hospital or nursing home care. Waiver serves a broader group of children than those who have terminal illness or life-limiting condition.
 - o Services covered: case management, bereavement services, expressive therapies, family palliative care education, home and vehicle modification, massage therapy, pain and symptom management
 - o Helpful links:
 - http://www.opwdd.ny.gov/opwdd_services_supports/supports_for_independent_and_family_living/Care_at_Home
 - https://www.health.ny.gov/facilities/long_term_care/docs/manual.pdf
 - Only for physically disabled children
 - Can apply even if you already have insurance
- **New York** 1915(c) waiver: “NY Bridges to Health for Children w/ SED (0469.R01.00), DD (0470.R01.00), and who are medically fragile (0471.R01.00) – just for children in foster care
- **North Carolina** 1915(c) waiver: “Community Alternatives Program for Children”
 - o For medically fragile children; covers palliative care which is said to include art therapy, music therapy, counseling, and bereavement counseling offered both to the child and to the family (<http://www2.ncdhhs.gov/dma/medicaid/capchildren.htm>)
 - o <http://www2.ncdhhs.gov/dma/mp/3K1.pdf>
 - Page 41: Description and overview of the palliative care covered for those with “life-threatening” illnesses:
 - What is covered under this plan:
 - o Counseling, Expressive therapy, Bereavement activities and opportunities for dialogue
 - Available after diagnosis with a “life limiting illness or condition”
 - Limitation: not available to beneficiaries of Medicaid or Medicare Hospice services
- **North Dakota** 1915(c) waiver: “ND Children’s Hospice” (0834.R01.00)
 - o Expands pediatric palliative care – instead of using the qualification of “terminal illness with life expectancy of 6 months,” it uses the language “life limiting illness. (California and Colorado do the same)
 - o <https://www.nd.gov/dhs/info/pubs/docs/medicaid/brochure-children-hospice-waiver.pdf>
 - o <http://www.hrrv.org/news/n-d-childrens-hospice-program-approved/>
- **North Dakota** 1915(c) waiver: Medicaid Waiver for Medically fragile Children (0568.R01.00)
 - o Ages 3-17; Provides in-home support and institutional respite care for children who are medically fragile and qualify for Medicaid
- **Ohio** Chapter 3712: Hospice Care <http://codes.ohio.gov/orc/3712>
- **Oklahoma** 1915(c) waiver: “OK In-Home Supports Waiver for Children” (0351.R03.00)
 - o Ages 3-17
- **Oregon** 1915(c) waiver: “OR Medically involved Children’s Waiver” (0565.R01.00)
 - o Ages 0-17; It directs the Department of Human Services (DHS) to apply for a Medicaid waiver irrespective of parental income. Services may include home nursing care, durable medical equipment, and respite care. OR Medically Fragile (Hospital) Model (40193.R03.00)
- **Pennsylvania: PPACA Section 2303**
 - o Went into effect upon the enactment of the PPACA, on March 23, 2010. States that “voluntary election of hospice care for a child cannot constitute a waiver of the child’s right to be provided with, or to have payment made for, services that are related to the treatment of the child’s condition, for which a diagnosis of terminal illness has been made.”
- **South Carolina** 1915(c) waiver: “SC Medically Complex Children” (0675.R01.00)
 - o Provides care coordination, respite (skilled and unskilled), pediatric medical day care, for medically fragile and technology dependent individuals ages 0-18
 - o For chronic conditions that are expected to last at least 12 months (so not for life-threatening illnesses necessarily)

- **South Carolina** 1915(c) waiver: SC Pervasive Developmental Disorder (0456.R01.00)
 - o Ages 3-10
- **South Dakota** 1915(c) waiver: “SD family support” (0338.R03.00)
 - o Ages 0-no max
 - o Provides personal care, respite, support coordination, supported employment, personal care 2, companion care, environmental accessibility adaptations, nutritional supplements, specialized medical adaptive equipment and supplies, vehicle mods for individuals with DD and IID
- **Texas** 1915(c) waiver: “TX Medically Dependent Children Program” (0181.R05.00)
 - o Ages 0-20
 - o Provides adaptive aids, FMS, flexible family support, minor home mods, transition assistance for medically fragile individuals
- **Texas** 1915(c) waiver: TX Youth Empowerment Services
 - o Ages 3-18
 - o Provides respite, adaptive aids and supports, community living supports, family supports, minor home mods, non-medical transportation, paraprofessional services, specialized therapies, supportive family-based alternatives, transitional services for individuals with SED
- **Utah** 1915(c) waiver: “UT Waiver for Technology Dependent, Medically Fragile Individuals” (40183.R04.00)
 - o Ages 0-20
 - Provides skilled nursing respite care, extended home health aide, extended private duty nursing, family directed support, FMS, family support services, in-home feeding therapy for medically fragile and technology dependent individuals
- **Utah** 1915(c) waiver: “UT Community Supports Waiver for Individuals with ID and Other Related Conditions”
 - o Ages 0-no max
 - o Behavioral Consultation, Chore Services, Companion Services, Day Supports, Emergency Response Systems, Environmental Adaptations, Extended Living Supports, Family/Ind. Training and Preparation, Financial Management Services, Homemaker Services, Living Start-up Costs, Massage Therapy, Medication Monitoring, Non-medical Transportation, Personal Assistance, Personal Budget Assistance, Residential Habilitation, **Respite Care**, Specialized Medical Equipment, Supported Employment, Supported Living, Waiver Support Coordination
- **Washington** 1915(c) waiver: “WA Children’s Intensive In-Home Behavioral Support” (40669.R01.00)
 - o Ages 8-20
 - o Personal care, respite, OT, PT, speech/hearing/language, assistive tech, behavior management/consultation...environmental accessibility adaptations, nurse delegation, sexual deviancy evaluation, specialized clothing, medical equipment and supplies, nutrition, psychiatric services, staff/family consultation/training, therapeutic equipment and supplies, transportation, vehicle mods for individuals with DD.

Hospice Expansion of 6-Month Life Expectancy Requirement **OR Expansive Definition of Terminal Illness**

- **Louisiana:** Defines “Children’s respite care center”: an autonomous, centrally administered, pediatric medical respite program providing a continuum of home, outpatient, and homelike inpatient care for Louisiana children living with **life-limiting illnesses** and their families. It employs an interdisciplinary team to assist in providing palliative care and supportive care, combined with curative treatment, to meet the special needs arising out of the physical, emotional, spiritual, social, and economic stresses which are experienced during life-limiting illnesses as well as during dying and bereavement if a cure is not attained.
<http://law.justia.com/codes/louisiana/2014/code-revisedstatutes/title-40/rs-40-2175.12>
- **Louisiana:** Defines pediatric as birth through age 20.
- **New Jersey** bill that acknowledges need to more respite facilities also uses the “life-limiting” language.
http://www.njleg.state.nj.us/2012/Bills/A4000/3558_S4.PDF
- **New York:** An Act to amend the public health law, in relation to the definition of palliative care.
 - o Uses “life-limiting” language.
 - o Conforms definition of palliative care to be in line with ACA
 - “Section 1. Legislative intent. The purpose of this act is to conform the concept of palliative care under article 40 of the public health law with that in sections 2997-c (palliative care patient information) and 2997-d (hospital, nursing home, home care, special needs assisted living residences and enhanced assisted living residences palliative care support) of the public health law.”
 - http://assembly.state.ny.us/leg/?default_fld=&bn=A02211&term=2015&Summary=Y&Text=Y -
- **North Carolina:** 1915(c) waiver “Community Alternatives Program for Children” is available for children with “life limiting” illnesses
- **North Dakota:** 1915(c) waiver: “ ND Children’s Hospice” (0834.R01.00)
- **Vermont:** <http://www.vtethicsnetwork.org/act60.html>
- **Washington:** 50.94(1)(a) defines terminal illness as 12 month life expectancy.
<http://docs.legis.wisconsin.gov/statutes/statutes/50/IV/94/1/a>

Legislative or Non-Legislative Focus on Increased Access to and Awareness of Respite and Palliative Care

Note: Nearly every, if not all, state includes palliative care within the definition of health care in the state code.

- **Alabama:** In 2012 passed the Alabama Lifespan Respite Resource Network Act, which created a coalition to (1) build partnerships and coordinate respite care efforts statewide (2) provide public awareness about respite to the citizens of Alabama, and, (3) identify, coordinate, and develop, community/funding resources for respite services.
 - o <http://www.alabamarespite.org/index.php/about-us/alabama-lifespan-respite-coalition>
- **Arkansas:** Held a conference recently
http://www.arhealthcare.com/sites/default/files/content/u34/Partners%20in%20Care%20Conference%20Registration%202015_Mailout.pdf
- **California:** Children’s Hospice and Palliative Care Coalition <http://www.chpcc.org/>
 - o Collaborates with CA Dept of Health Care Services
- **Connecticut:** Palliative Care Advisory Council created by Public Act 13-55
<https://www.cga.ct.gov/2013/act/pa/2013PA-00055-R00SB-00991-PA.htm>
- **Florida** Title XLIV 765.102
 - o “The Legislature recognizes the need for all health care professionals to rapidly increase their understanding of end-of-life and palliative care. Therefore, the Legislature encourages the professional regulatory boards to adopt appropriate standards and guidelines regarding end-of-life care and pain management and encourages educational institutions established to train health care professionals and allied health professionals to implement curricula to train such professionals to provide end-of-life care, including pain management and palliative care.”
 - o Defines palliative care: “Palliative care is the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. Palliative care is especially suited to the care of persons who have incurable, progressive illnesses.”
- **Illinois** Pediatric Palliative Care Act
<http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=3247&ChapterID=28>
- **Maryland:** No relevant legislation found
- **Maine:** An Act to Improve the Quality of Life of Persons with Serious Illnesses – governor vetoed in June 2015 and his veto was overridden
http://legislature.maine.gov/legis/bills/bills_127th/chapters/PUBLIC203.asp
- **New Hampshire:** CHAPTER 78 HB 831 - FINAL VERSION (2003) “An Act adding duties to the oversight committee on health and human services.” – One goal was “Identifying strategies to increase earlier participation in hospice services and remove barriers for those who desire hospice.”
(<http://www.gencourt.state.nh.us/index/QueryResults.aspx>)
- **New Jersey:** Bill about licensing more of these facilities because there isn’t enough respite care in NJ.
 - o “The bill defines “pediatric respite care facility” to mean a facility licensed by the DOH that provides home-like care in a facility for two weeks or less of respite care, or as necessary for end-of-life care or as medically necessary for children up to age 21 with limited life expectancies or complex, life-limiting illnesses and support for their families, and employs an interdisciplinary team to assist in providing curative treatment when possible, palliative care, and supportive services to meet the physical, emotional, spiritual, social, and economic needs of children and their families during illness, as well as during dying and bereavement if no cure is attained.”
http://www.njleg.state.nj.us/2012/Bills/A4000/3558_S4.PDF

Legislation Still in Process

- **Georgia** HB 509 currently still alive: Georgia Palliative Care and Quality of Life Advisory Council
<http://www.legis.ga.gov/Legislation/en-US/display/20152016/HB/509>
 - o A BILL to be entitled an Act to amend Chapter 7 of Title 31 of the Official Code of Georgia Annotated, relating to health care facilities, so as to implement initiatives to improve quality and delivery of patient centered and family focused palliative care in this state; to provide for legislative intent; to provide for definitions; to create the Georgia Palliative Care and Quality of Life Advisory Council; to establish a state-wide Palliative Care Consumer and Professional Information and Education Program; to provide for related matters; to repeal conflicting laws; and for other purposes.
- **Massachusetts** Senate Bill S1138: An act regarding the pediatric palliative care program
<http://openstates.org/ma/bills/189th/S1138/>
- **Missouri** HB 808 currently going through the House:
<http://www.house.mo.gov/billsummary.aspx?bill=HB808&year=2015&code=R>
 - o Establishes the Missouri Palliative Care and Quality of Life Interdisciplinary Advisory Council and the Palliative Care Consumer and Professional Information and Education Program

Failed Legislation

- **Florida** HB511 was introduced in January 2015 but died in the Health Quality Subcommittee:
<http://www.flsenate.gov/Session/Bill/2015/0511/BillText/Filed/PDF>
- **Florida** SB438 was introduced in January 2015 but died in Fiscal Policy:
<https://www.flsenate.gov/Session/Bill/2015/0438/BillText/Filed/PDF>
- **Pennsylvania SH 2337** – Section 505 would require that private insurers follow the Affordable Care Act’s requirements for concurrent care for children.

State Advocacy Groups or Coalitions, Group Homes, Respite Homes

- **Arizona:** Ryan House <http://www.ryanhouse.org/>
 - o Designed to deliver multiple adaptive modes of on-site care, Ryan House embraces all children and their families as they navigate life-limiting or end-of-life journeys. Here, we are realizing both the philosophy and the practice of pediatric palliative care. We are the only organization of our kind in the Southwest, and one of two in the country. Our services are provided at no cost to families
 - o 28 days of respite care per year
- **Delaware:** <http://www.exceptionalcare.org/> skilled pediatric nursing facility with 10 rooms
- **Florida:** Pediatric Palliative Care Consortium – Joint project between Florida Association of Children’s Hospitals and Florida Hospices and Palliative Care, Inc. <http://www.floridahospices.org/Website%20-%20Files/FL%20PPC%20Consortium%20Description.pdf>
- **Idaho:** Quality of Life Coalition
 - o Hasn’t done much for pediatric palliative care but recognizes that there is work to be done
- **Illinois:** Greater Illinois Pediatric Palliative Care Coalition <http://newsite.gippcc.org>
- **Kansas:** Pediatric Hospice and Palliative Care Coalition <https://www.facebook.com/ks.ped.hpcc>
- **Michigan:** No state coalition currently. MAPPS (Michigan Alliance for Pediatric Palliative Services) did exist in the past.
- **Maryland:** No state coalition currently.
- **Missouri:** Hospice and Palliative Care Association <http://www.mohospice.org/>
 - o MHPCA is a state-wide non-profit organization dedicated to supporting and strengthening coordinated care for terminally ill Missourians and their families through the advancement of hospice and palliative care
- **Nevada:** CareOusel Pediatrics <http://careouselpediatrics.com>
- **New Jersey**
 - o Circle of Life Home <http://www.circleoflifenj.org/en/>
 - o Liam’s Room
- **North Carolina:** Pediatric Palliative Care Coalition of NC - <http://www.pedcomalliance.org>
- **Ohio:** Ohio Pediatric Palliative Care and End of Life Network
- **Pennsylvania:** Pennsylvania Pediatric Care Coalition <http://www.ppcc-pa.org>
- **South Carolina:** Hands of Hope <http://www.handsofhopesc.net>
- **Texas:** Pediatric Palliative Care Consortium <http://www.texasppcc.org>

Other Resources

- **Arizona** Resource guide: <http://www.azaap.org/Resources/Documents/PalliativeCare.pdf>
- **Florida** Comparison of pediatric services in Florida (hospice, concurrent care for Medicaid recipients, home health, CMS) <http://floridahospices.org/Website%20-%20Files/PedComparisonChart.pdf>
- **Missouri** Resource guide: http://www.mohospice.org/subpage.php?page=palliative_care
- **National** Hospice and Palliative Care Organization: <http://www.nhpco.org/pediatric>
- **International** Children’s Palliative Care Network upcoming conference: <https://www.facebook.com/events/1665739066972714/>
- Health and Disability Working group on Financing Pediatric Palliative and Hospice Care Programs: <http://hdwg.org/catalyst/node/197>