



APPENDIX 1

CHI Program for All-Inclusive Care

for Children and Their Families™ (CHI PACC®)

CHI PACC® Standards of Care and Practice Guidelines

A CHI PACC® program provides a continuum of care for children and their 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. The CHI PACC® program's integrated, coordinated continuum of care is provided across all settings, 24 hours a day, 7 days a week.

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Introduction

PURPOSE

The CHI PACC[®] Standards listed below outline basic essential model of care components for the development of local Programs of All-Inclusive Care for Children/Adolescents who are diagnosed with life-threatening conditions and the members of their families. The goal of CHI PACC[®] is to expand access to curative and palliative services beyond the scope of traditional hospice benefit.

The accompanying CHI PACC[®] Practice Guidelines represent best practices in the goal of providing optimal curative and palliative care to these children/adolescents and families. CHI PACC[®] programs are expected to continuously evaluate and improve the quality of the services and supports provided to program participants.

STATUS

CHI PACC[®] is an authorized demonstration program administered by Children's Hospice International in collaboration with the Centers for Medicare & Medicaid Services (CMS) and the United States Department of Defense. This program provides an opportunity to establish CHI PACC[®] projects with federal waivers or other mechanisms that remove existing regulatory barriers and redistribute funding.

PROGRAM EXPECTATIONS

The CHI PACC[®] Standards outline the components of the model of care. CHI expects that programs will establish plans by which the Standards will be implemented in an orderly, timely manner with timelines and measurable objectives.

The CHI PACC[®] Practice Guidelines outline the components of a fully developed CHI PACC[®] program. CHI expects that programs will establish plans by which the Practice Guidelines will be implemented in a manner that facilitates the provision of optimal care.

STANDARDS OF CHI PACC[®]

Implementing CHI PACC[®] Standards with their accompanying Practice Guidelines will assist CHI PACC[®] programs to establish health care systems which will help implement the new model of care. The following is a list of the core Standards of the CHI PACC[®] model, which must be adhered to in the development of any CHI PACC[®] program.

1. Creation of a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical, nursing, psychosocial, or spiritual service needed for the child or

- family unit.
2. Integrations of a curative care with palliative care and community-based supportive services.
 3. Establishment of a system of comprehensive care with one point of entry providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.
 4. Redistribution of funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.

EXPECTED GENERAL CLINICAL OUTCOMES

The CHI PACC[®] Standards/Practice Guidelines establish a functional framework in which clinicians are not restricted by artificially limiting provider regulations and reimbursement. This model allows for the development of responsive client-based, client-determined, systems of clinical care with improved clinical outcomes and consumer satisfaction. These outcomes will address:

1. Early implementation of palliative care integrated with medical treatments of the life-threatening condition with the goal of addressing quality of life needs and issues through palliative care.
2. Expanded availability of home and community based services to reduce dependence on institutional care.
3. Enhanced support services to maintain family cohesion, sense of control, satisfaction with care, and informed decision making.
4. Facilitation of transitions from settings of care due to progression of condition.
5. Advanced preparation and support of families when end-of-life care becomes imminent.

EXPECTED FINANCIAL OUTCOMES FOR PAYERS CHI PACC[®]

The implementation of CHI PACC[®] programs will have a “cost neutral” impact upon the total expenditures of public and private payers. This will be achieved by cost-offsetting to fund expanded palliative care services through reducing expenditures in the following ways:

1. Preventing unnecessary Emergency Room and Hospital admissions.
2. Facilitating earlier discharges from hospitals into home care.
3. Performing some treatments and procedures, such as chemotherapy, at home.
4. Supporting families to provide end-of-life care at home rather than the hospital, as appropriate.
5. Providing “hospice in the hospital” when it is appropriate for a terminal admission.

TECHNICAL ASSISTANCE

CHI is available to answer any questions regarding the satisfaction or implementation of these Standards/Practice Guidelines. For assistance, please contact CHI at 800-2-4-CHILD, or at info@chionline.org.

DESCRIPTION OF KEY TERMS

All Settings of Care:	Describes any location in which services are provided, such as home, clinic, respite facility, hospital, etc.
Child/Adolescent:	Identifies anyone within program defined guidelines who is eligible for admission to a CHI PACC [®] program due to diagnosis of a life-threatening condition, regardless of chronological age, developmental stage, or gender.
Comprehensive Care:	Describes broad range of interdisciplinary services available in all settings of care to meet the medical, nursing, psychosocial, spiritual, and practical concerns and needs of those served by a CHI PACC [®] program.
Concurrent Care:	Care that integrates treatments aimed at cure or disease management with treatments aimed at managing symptoms through palliative care.
Continuity of Care:	Describes consistency in care and services across the entire continuum of care due to the portability of the plan of care and its goals in all settings of care, including ease of transitions from one setting to another.
Continuum of Care:	Describes the “seamless” array of services and providers available from the beginning of care at diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation to an adult program of care, or the completion of bereavement of care.
Diagnosis of Life-threatening Condition:	A formal evaluation made by a licensed physician indicating the existence of a condition that has the potential of limiting the life-expectancy of the child/adolescent.
Disease Treatment:	Medical interventions and procedures implemented by written orders of a licensed physician intended to treat the condition that is threatening the life-potential of a child/adolescent, whether the goal is the hope of eliminating the condition, achieving remission of the progression of the condition, or extending the life-potential of the child/adolescent without altering the basic underlying condition.
Family:	Identifies those persons who constitute the inner circle of physical, psychosocial, spiritual, and emotional relationships with the child/adolescent who is diagnosed with a life-threatening condition.
Children/Adolescents With Life-Threatening Categories:	Children/adolescents who fall into Conditions: <ol style="list-style-type: none">1. Children/adolescents for whom curative treatments are possible and likely to succeed, and who could benefit from palliative care.2. Children/adolescents for whom curative treatments are possible and fail, and who need palliative care.

3. Children/adolescents for whom extensive periods of curative or palliative treatment may extend their lives, even though death is likely.
4. Children/adolescents with chronic and/or progressive conditions for which there is no cure and whose treatment is primarily or exclusively palliative.
5. Children/adolescents with severe neurological disabilities causing susceptibility to complications which affect the child/adolescent's ability to function or quality of life, and symptoms causing discomfort.
6. Children/adolescents and families who are likely to experience a great deal of distress, disruption and suffering as a result of the condition.

Palliative Care:	An approach to provide total comprehensive comfort-oriented care for children/adolescents/families as a whole and whose purpose is to enhance quality of life, minimize suffering, relieve causes of distress, and provide emotional and spiritual support through interdisciplinary services and interventions.
Parent:	Identifies the individual(s) who have the legal or guardianship responsibility for the well-being and care of the child/adolescent diagnosed with a life-threatening condition.
Program of All-Inclusive Care:	Model of care providing enhanced services to children/adolescents with life-threatening conditions and their families.
CHI PACC [®] Program:	An organized program qualified to participate in the Children's Hospice International demonstration project for children/adolescents diagnosed with life-threatening conditions and the members of their families, abbreviated CHI PACC [®] .
Referral:	The point at which a physician, upon identification of a life-threatening condition, or symptoms of a life-threatening condition affecting the ability of a child/adolescent to function and/or have an acceptable quality of life, contacts the local CHI PACC [®] program for the child/adolescent to be considered for admission.

Principles of Care with Practice Guidelines

ACCESS TO CARE

Principle:

Children and adolescents diagnosed with life-threatening conditions and the members of their families have ease of access to a comprehensive, coordinated, competent continuum of care in their communities.

Practice:

- A.C.1. Outreach plans are implemented across all geographic areas in which CHI PACC[®] programs are available, in order to ensure eligible families, providers, and community organizations have adequate information to facilitate referral to the program. Programs must be comprised of adequate professional medical, social, and supportive staff to serve the needs of those eligible families in the program's service area.
- A.C.2. CHI PACC[®] services are culturally relevant, sensitive, and available to children/adolescents and families of the diverse cultures within the program's service area, and in language that is understandable.
- A.C.3. CHI PACC[®] program provides communication supports to assist children/adolescents and family members that are sensory or cognitively impaired.
- A.C.4. The CHI PACC[®] program provides organized outreach, ongoing education, accurate information about services, and timely resources to all potential referrers to the CHI PACC[®] palliative care program to enhance their ability to identify potentially appropriate children/adolescents and families for referral.
- A.C.5: Children/Adolescents in CHI PACC[®] Programs have access to treatments and therapies aimed at cure, condition modification or life extension concurrent with and integrated with treatments and services aimed at palliative care goals throughout the entire course of their care.

CHILD/ADOLESCENT/FAMILY AS UNIT OF CARE

Principle:

The CHI PACC[®] care continuum provides care that is consistently child/adolescent oriented and family-centered in its philosophy, values, practices and operation. All care seeks to support and enhance the life-experience and its quality for each child/adolescent/family unit as defined by their culture, values, beliefs, priorities, circumstances, choices and structure.

Practice:

- U.C.1. Care is provided to children/adolescents within the context of each one's age, developmental stage, level of understanding, communication ability, as well as severity of life-threatening condition and its symptomology. Each child/adolescent's own interest, hopes, fears, values, beliefs, and needs are solicited to ensure to the fullest degree possible the integration of the child/adolescent's own point of view and perspective in planning, implementing and evaluating services.
- U.C.2. Care is available to all members of the family according to assessed needs and individual choice, including siblings, parents, grandparents and/or other individuals significant to the family unit.
- U.C.3. Care affirms the uniqueness and distinctiveness of each family's own system of inter-relationships, roles, decision-making processes, and organizational structure.
- U.C.4. Care is implemented to encourage and assist each child/adolescent/family unit to live as normal as is possible under existing circumstances, continue in their customary roles and activities as much as possible and participate in the communities of which they are a part.
- U.C.5. Each family unit is assessed in order to establish a plan for meeting the ongoing family member's involvement in caregiving at home. Each family is provided education, training and support for its care giving activities and responsibilities. Careful attention is given to helping families be open to receiving additional support through volunteers, respite care, ancillary staff support, as well as assistance from others in the community.

ETHICS

Principle:

The CHI PACC[®] program operates its services for children/adolescents and family members according to generally accepted ethical standards.

Practice:

- E.1. CHI PACC[®] service staff respect and honor the individuality, uniqueness, and humanness of each child/adolescent and family member, ensuring their inclusion in decision-making to the full extent possible, and consistent with the beliefs and values of their culture, spirituality and family structure.
- E.2. CHI PACC[®] program staff ensures the appropriate, necessary, and responsible use of all information about each child/adolescent and family member, and protects the confidentiality of all communications, documents, records and materials from unauthorized exposure or use.
- E.3. CHI PACC[®] service staff ensures that each child/adolescent and family member receives information concerning the life-threatening conditions, diagnosis, condition trajectory, treatment options and their side effects, symptoms and their treatment options and side effects, and their quality of life implications in language understandable to them, and within a supportive respectful communication environment.
- E.4. CHI PACC[®] program staff ensures that its services are available and accessible to any child/adolescent diagnosed with any life-threatening condition and family members without discrimination for reason of age, gender, racial or ethnic origin, national origin, geographic location in service area, language, religion or spirituality, sexual orientation, diagnosis, disability, family structure or status, ability to pay or potential cost of care to the program.
- E.5. The CHI PACC[®] service staff implements treatments and services whose intentions are designed to achieve the maximum beneficial child/adolescent and family outcomes possible with the least amount of negative impact possible on quality of life goals.
- E.6. The CHI PACC[®] program staff insures that its resources provide adequate support for the services provided and the continuing development of the program and an appropriate system of accountability is in place.
- E.7. The CHI PACC[®] program staff provides an ethics consultation and educational service to assist program personnel, family members and the child/adolescent living with a life-threatening condition when there are conflicts about choices for services and treatments.

MANAGEMENT AND OPERATIONS

Principle:

The CHI PACC[®] program is a comprehensive integrated continuum of services operating according to nationally recognized standards of care, evidence based treatments, and best practices. It is accountable to all appropriate licensure, regulatory and accreditation bodies and to the communities in which the families and children/adolescents live.

Practice:

- M.O.1. The CHI PACC[®] program establishes and maintains current, accurate, adequate and comprehensive management of all aspects of the program, provides all needed services, manages all personnel, coordinates all collaborative relationships, assures fiscal, clinical, and managerial accountability and ongoing evaluation and program improvement and development.
- M.O.2. The CHI PACC[®] program operates within the requirements all local, state and federal laws and regulations that govern the establishment and delivery of CHI PACC[®] services by various providers, as well as qualifications of professionals and volunteers delivering services.
- M.O.3. The CHI PACC[®] program provides a clear, accessible and responsive grievance procedure for children/adolescents and family members which outlines how to voice concerns or complaints about services and care without jeopardizing their relationship to the CHI PACC[®] program or access to needed services.
- M.O.4. The CHI PACC[®] program ensures that all personnel, including administrative, managerial, clinical, supportive and voluntary are qualified and oriented for their positions and responsibilities, operate with a current accurate job description, have a designated supervisor/administrator, have access to appropriate support and ongoing training and skills building, and are evaluated on a routine basis by criteria based on their job description and responsibilities.

INTERDISCIPLINARY TEAM

Principle:

Children/adolescents living with life-threatening conditions and the members of their families have a wide range and intensity of ongoing and changing stresses, needs, problems and hopes requiring care. This complex need for care requires the expertise and competence of many disciplines, perspectives and skills working together as an integrated, comprehensive, coordinated team to provide effective care.

Practice:

- I.T.1. The CHI PACC[®] core team is staffed by an appropriate and representative range of medical, nursing, psychosocial and spiritual professionals, ancillary and support personnel, and volunteers adequate to meet the need for care. The team incorporates and integrates members of many disciplines, and may include pediatricians, pediatric medical and nursing specialists, advance practice nurses, high tech nurses, physician specialists, physician assistants, nurse assistants, social workers, chaplains, home health aides, home makers, in-home respite workers, physical therapists, occupational therapists, speech and language therapists, nutritionists, art therapists, music therapists, play therapists, recreation therapists, pediatric psychiatrists and/or psychologists, massage therapists, and others according to their availability in the program service area.
- I.T.2. The CHI PACC[®] core team is responsible to provide ease of admission, comprehensive assessments, identification and clarification of goals of care, development and implementation of a current plan of care, facilitate continuity of care in all settings, provide effective symptom management, counseling and supportive services for those it serves, including end-of-life care as appropriate.
- I.T.3. The child/adolescent and family are included as members of the team assigned to their care, and encouraged to manage the care according to their desire and abilities.
- I.T.4. The CHI PACC[®] core team has a qualified medical director, nurse manager and psychosocial/spiritual care coordinator/supervisor, and a designated team coordinator.
- I.T.5. The CHI PACC[®] core team establishes and maintains an effective system to ensure timely sharing of information between all team members and the coordination of services.
- I.T.6. The CHI PACC[®] core team collaborates and coordinates care with the professionals in other settings.
- I.T.7. CHI PACC[®] core team members are qualified in their particular discipline, role and

responsibilities by training and/or experience, and certification and/or licensure when appropriate or required.

- I.T.8. CHI PACC[®] core team members receive educational, emotional and spiritual support appropriate to their roles and responsibilities, setting of care, and need.
- I.T.9. Essential medical, nursing, psychosocial and spiritual services are available to children/adolescents and family members 24 hours a day, each day, in all settings of care.
- I.T.10. In communities in which particular pediatric, medical or palliative care expertise is not available, the team has a documented plan and method to access that expertise.

ADMISSION PROCESS

Principle:

The CHI PACC[®] program maintains a barrier-free process which facilitates ease of entry into the program for children/adolescents and their families, timely response to initial and presenting needs and problems, and access to on-call care at the time of admission.

Practice:

- A.P.1. The CHI PACC[®] program provides ease of entry into its services for children/adolescents and their families and monitors the process of admission, recognizing that at the time of referral, many children/adolescents and families may be in crisis and need immediate care.
- A.P.2. An initial plan of care is established promptly after admission to guide care and services, (recognizing that it may take time to develop a trusting relationship between the child/adolescent and family and CHI PACC[®] staff) to assess the comprehensive needs of the child/adolescent and each family member, respond to presenting needs or problems, negotiate goals of care, receive, disseminate and evaluate all relevant and necessary information from the child's/adolescent's primary medical team and/or hospital.
- A.P.3. The CHI PACC[®] program acquires all necessary and needed demographic information, relevant medical history, and documentation about disease management and/or medical therapies at the time of referral and admission.
- A.P.4. Admission to the CHI PACC[®] program is made on the basis of the need for care and criteria for CHI PACC[®] eligibility without regard to age, gender, racial or ethnic origin, national origin, geographic location in service area, language, religion or

spirituality, sexual orientation, diagnosis, disability, family structure or status, ability to pay or potential cost of care to the program.

- A.P.5. CHI PACC[®] program eligibility criteria are available in language and terminology understandable to nonprofessionals, and family members and available in the primary languages spoken in the service area.
- A.P.6. Admission to CHI PACC[®] program is admission to the entire continuum of care and its comprehensive system of services.

COMPREHENSIVE ASSESSMENT PROCESS

Principle:

Comprehensive interdisciplinary assessment instruments are utilized by the CHI PACC[®] care team to insure that the goals of care and plan of care are based on needs identified as important to the child/adolescent and family. This assessment process is ongoing as needs, circumstances and hopes change during the course of care in response to the progression of the child/adolescent's life-threatening condition and its symptomology.

Practice:

- C.A.P.1. CHI PACC[®] interdisciplinary staff members assess the comprehensive ongoing physical, psychosocial, emotional, spiritual, practical and financial situations, circumstances, needs, hopes, concerns and goals of each child/adolescent and family member, from the time of admission and continuing throughout the entire course of care, including end-of-life care and bereavement.
- C.A.P.2. CHI PACC[®] team assessments take into consideration the child's/adolescent's developmental stage, spirituality, diagnosis, trajectory of life-threatening condition, treatment choices and protocols, and progressive symptomology, whether caused by the progression of the condition or its treatments.
- C.A.P.3. CHI PACC[®] team assessments are made within the understanding, language, culture, values, beliefs, hopes, family structure and social context of each child/adolescent and family.
- C.A.P.4. CHI PACC[®] team assessments are utilized to gather all the information needed for implementing services, and to provide a means for CHI PACC[®] staff members to build relationships with each child/adolescent and family, offer education and information about choices and options, and provide support.

GOALS OF CARE

Principle:

Consistent goals of care guide the establishment and implementation of all services in all care settings and by all providers of services. These goals reflect the culture, hopes, values, beliefs and quality of life needs of children/adolescents and their families in response to the assessed situation of the life-threatening condition. The goals are utilized to establish the integrated treatment of the disease or life-threatening condition along with the palliative care plan of care and array of services to be provided. All medical treatment goals and palliative goals are in response to the goals of the child/adolescent/family.

Practice:

- G.O.C.1. In order for children/adolescents/families to formulate reasonable, realistic goals of care within hope for cure, the most accurate truthful information is provided about the condition diagnosed, its symptomology, treatment options and their side effects and expectations, life expectancy, possible family burden, and opportunities for quality of life.
- G.O.C.2. The CHI PACC[®] Interdisciplinary Team collaborates with the primary care/disease management personnel and palliative care personnel to assess each child/adolescent's and family's life goals to offer best practices and supportive services to the child/adolescent and family within the context of these goals.
- GO.C.3. The CHI PACC[®] Interdisciplinary Team establishes methods to evaluate, re-assess and adjust both the global and specific goals of care throughout the progress of the life-threatening condition and its care.
- G.O.C.4. The CHI PACC[®] Interdisciplinary Team utilizes the child/adolescent's and family's goals to frame discussions, education, and decision-making regarding the progression of the life-threatening condition, its symptomology, treatment options and achievable results.
- G.O.C.5. The CHI PACC[®] Interdisciplinary Team members who are directly responsible for the care of each child/adolescent and family unit, orient staff members in all settings of care to the child/adolescent and family's life goals, disease-treatment goals, and the palliative care goals as settings of care change.
- G.O.C.6. The CHI PACC[®] Interdisciplinary Team members responsible for the care of each child/adolescent/family unit ensure that discussions concerning the goals of care and their implications for services are conducted with language and vocabulary understandable to them, are done in a way that empowers the decision making choices of child/adolescent and family, and provides emotional and spiritual support.
- G.O.C.7. The CHI PACC[®] Interdisciplinary Team members responsible for the care of each child/adolescent/family unit recognize that there will be times and occasions in

which the child/adolescent and family members will experience ambiguity, conflict and/or unrealistic expectations regarding the goals of care, treatment therapies, and choices available to them, as well as potential differences about those choices, and their potential results. This ambiguity and/or conflict also may be present in the CHI PACC[®] team members and/or disease treatment professionals as well. Every effort is made to resolve the occasions through processes of mediation, consensus building, and provision of support, counseling and education.

- G.O.C.8. The CHI PACC[®] program provides support to and advocacy for the child/adolescent/family when there is a disconnect between the culture, values, and goals of the child/adolescent/family and those delivering services in any setting. A process of mediation and consensus building should be utilized to resolve occasions of conflict over the goals of care and their implications for services, procedures and treatments.

PLAN OF CARE

Principle:

An up-to-date comprehensive written plan of care is individualized to meet the specific needs, hopes and goals of each child/adolescent and family, addresses the medical, nursing, psychosocial, spiritual, and practical concerns and problems they have identified with achievable outcomes and results, and integrates the activity of the team implementing *medical* treatment services and the team implementing *palliative* services.

Practice:

- P.O.C.1. The CHI PACC[®] Interdisciplinary Team establishes a comprehensive plan of care appropriate for each child/adolescent and family based on comprehensive ongoing assessment of needs, hopes and goals identified by the child/adolescent and family unit.
- P.O.C.2. CHI PACC[®] Interdisciplinary Team members monitor the plan of care integrating treatment goals and procedures of the life-threatening condition and palliative care goals and services.
- P.O.C.3. The CHI PACC[®] Interdisciplinary Team ensures that each child/adolescent and family has direct input into the creation and establishment of the plan of care.
- P.O.C.4. The CHI PACC[®] plan of care identifies a family member and a CHI PACC[®] team member, as the point of contact for the coordination of services and care, and the resolution of problems.
- P.O.C.5. The CHI PACC[®] Interdisciplinary Team monitors, reviews and revises each plan of

care on a regular and ongoing basis as goals, needs and hope change and the disease and symptoms progress.

- P.O.C.6. The CHI PACC[®] Interdisciplinary Team establishes mechanisms to ensure the portability of the plan of care in all settings of care and communication with staff members of the plan of care when a change in the setting of care occurs.
- P.O.C.7. The CHI PACC[®] program ensures that appropriately signed consents are negotiated and documented for the initiation or withdrawal or withholding of treatment.

CONTINUITY OF CARE

Principle:

CHI PACC[®] service delivery is based on a therapeutic relationship between child/adolescent, family members, and CHI PACC[®] team members. It maintains an integrated coordinated continuum of community based home care, out patient services, respite care, supportive services, primary medical and inpatient care, end-of-life care, and community services. The CHI PACC[®] team ensures continuity and consistency of care, in any setting, is provided from the time of admission to the conclusion of bereavement services or discharges from the program and provides a system of care management to assist each child/adolescent/family unit. This continuity also extends to relationships important to the child/adolescent and family, such as school, religious affiliation, and community activities.

Practice:

- C.C.1. CHI PACC[®] medical, nursing, psychosocial and spiritual care is available on a consistent basis, 24 hours a day in all settings of care, to child/adolescent and family members.
- C.C.2. Appropriate members of the CHI PACC[®] program are available to children/adolescents and families at all times when the office is closed.
- C.C.3. The CHI PACC[®] program has a communication system that ensures the confidentiality and privacy of child/adolescent and family information, can be used to update team members about each child/adolescent's and family's status, and facilitates a timely response to changing needs and or problems.
- C.C.4. The CHI PACC[®] program has a functioning continuum of care that ensures the portability of goals of care and the plan of care, and access to needed services as settings of care change.
- C.C.5. The CHI PACC[®] program maintains all required and appropriate documents and clinical records, maintains their confidentiality, ensures their safety, and appropriate

clinical use.

- C.C.6. The CHI PACC[®] program has written policies and procedures for transitioning a child/adolescent who reaches adulthood and the family to the new legal status of the child/adolescent, which includes continuity with changes in providers, payer sources, status of legal documents, and treatment options and choices.

SYMPTOM MANAGEMENT

Principle:

The range and intensity of symptoms which cause distress to the child/adolescent and family are managed to achieve the most attainable quality of life for child/adolescent and family within the context of their culture, beliefs, values and goals. Children/adolescents and their families must have access to care which is both competent and compassionate.

Practice:

- S.M.1. The CHI PACC[®] Interdisciplinary Team assesses all symptoms which cause distress or discomfort, whether as the result of progression of the life-threatening condition or its treatment.
- S.M.2. The CHI PACC[®] Interdisciplinary Team identifies each distressing symptom, such as pain, dyspnea, fatigue, loss of appetite, loss of body image, constipation, diarrhea, vomiting, and loss of sleep and assesses each for its etiology, best practice evidence-based treatments, and range of choices for treatment.
- S.M.3. The CHI PACC[®] Interdisciplinary Team members discuss, evaluate and implement complementary, alternative and culturally relevant therapies and treatments important to children/adolescents and their families as appropriate to enhance the therapeutic environment.
- S.M.4. Members of the CHI PACC[®] Interdisciplinary Team provide clear, accurate information about evidence-based treatments and alternatives as objectively as possible to each child/adolescent and family to assist them in making the most appropriate choices for treatment options according to their own values, beliefs and goals.
- S.M.5. The CHI PACC[®] Interdisciplinary Team encourages consistency of symptom management services and treatments in all settings of care by all providers of care.
- S.M.6. The CHI PACC[®] program has clinical expertise through a competent medical and nursing staff to provide effective state-of-the-art symptom management, and access to specialists as may be required or needed.

COUNSELING AND SUPPORTIVE CARE

Principle:

The diagnosis of a child/adolescent at any age or stage of development with a life-threatening condition initiates a life-changing crisis within the family that turns their world, customary roles, activities, assumptions and expectations of each member “upside down.” These children/adolescents and family members must have access to a comprehensive, coordinated, competent continuum of counseling and supportive services to assist them with the physical, emotional and spiritual issues, interpersonal dynamics and psychosocial dimensions of their experience.

Practice:

- C.S.C.1. The CHI PACC[®] Interdisciplinary Team identifies the initial ongoing and changing physical, psychosocial, emotional and spiritual issues, concerns, conflicts, priorities and needs of each child/adolescent and family member, assesses and evaluates each for the most appropriate response, integrates this into the written goals and plan of care, and assigns appropriate team members to implement services.
- C.S.C.2. The CHI PACC[®] program does not require or advocate a “right way” for children/adolescent and a family member to believe, cope, make decisions, grieve, or die but recognizes the deeply personal and individual nature of this experience. CHI PACC[®] team members provide counseling and supporting services which build upon each family member’s own emotional and spiritual strengths, coping mechanisms, priorities, communication styles, belief and value systems, cultural and ethnic values, and social resources.
- C.S.C.3. The CHI PACC[®] program facilitates the provision of adequate counseling and supportive services in all settings of care.
- C.S.C.4. The CHI PACC[®] program has clinical expertise through competent counseling, social work and chaplain staff, as well as childlife and childcare specialists.

VOLUNTEER SERVICES

Principle:

Trained and screened volunteers provide an opportunity for members of the community, including children and adolescents, to become directly involved in the care of children/adolescents living with life-threatening conditions, their families and the bereaved, as well as to serve the CHI PACC[®] program in other supportive and organizational capacities.

Practice:

- V.S.1. The CHI PACC[®] program has a structured, organized and active volunteer program adequate to support the care needed by children/adolescents and their families, as well as to meet other needs within the CHI PACC[®] program for volunteer support.
- V.S.2. The CHI PACC[®] volunteer program is managed by a designated, qualified supervisor/coordinator that is a member of the CHI PACC[®] Interdisciplinary Team and meets regularly with them.
- V.S.3. CHI PACC[®] program volunteers are considered non-salaried staff members and are managed and supervised accordingly.
- V.S.4. All volunteers are appropriately recruited, screened, trained, assigned, supervised and evaluated on the basis of their roles and responsibilities.
- V.S.5. Volunteers may include children and adolescents.
- V.S.6. CHI PACC[®] volunteer services to children/adolescents and families are initiated according to the assessed need and consent of the child/adolescent and family.
- V.S.7. CHI PACC[®] volunteers have access to an organized program of ongoing education and support.
- V.S.8. CHI PACC[®] volunteer services are documented and reports provided on kinds of services provided, hours of services provided and other activities undertaken, as well as the financial value of these services to the program.

BEREAVEMENT PROGRAM

Principle:

Family members of children/adolescents who die may continue to need supportive and/or professional services following the child's/adolescent's death for a period of time that varies among families and family members. The overall goal of bereavement care is to assist family members to reintegrate themselves into the communities of which they are a part and to find their long-term support in their communities.

Practice:

- B.P.1. The CHI PACC[®] program has a structured, organized, adequate program of bereavement services for surviving family members and/or significant others, including linkage to support organizations and services in the community.
- B.P.2. The CHI PACC[®] bereavement program is managed by a designated, qualified supervisor/coordinator who is a functioning member of the CHI PACC[®] Interdisciplinary Team and meets regularly with them.
- B.P.3. The CHI PACC[®] bereavement program has professional and/or volunteer staff members adequate and competent to meet the range of services needed by family members, including siblings.
- B.P.4. The CHI PACC[®] Interdisciplinary Team members who were involved in the care of families before the child died provide an assessment of the level of risk and need for services of the bereavement program by family members.
- B.P.5. All CHI PACC[®] professional and volunteer staff members in other settings of care have access to bereavement services as needed.
- B.P.6. The CHI PACC[®] bereavement program establishes a written bereavement plan of care based on an assessment of needs for each family member receiving bereavement services until the person is discharged from the program.
- B.P.7. The CHI PACC[®] bereavement team members have access to an organized program of education, supervision, support and evaluation.
- B.P.8. CHI PACC[®] bereavement services are documented and reports provided on services and their utilization.

RESEARCH & EVALUATION

Principle:

The CHI PACC[®] care program acknowledges the importance of developing evidence to support the most effective care practices for children, families, providers, and health systems concerning comprehensive services for children diagnosed with life-threatening conditions and their families. CHI PACC[®] programs accept the responsibility to participate in a variety of research activities, including those that may have scientific value or others that may guide program improvements or meet reporting requirements. These diverse research activities will occur in community and clinical care settings, and shall extend to bereavement services as appropriate. While these research activities may vary in methodology and setting, they will all provide opportunities for patients, families and providers to assess the performance of programs and services in systematic, confidential, and valid ways. These research activities will share the general purposes of improving the quality of pediatric care and promoting optimum outcomes for patients, families, providers, and health systems. These research efforts will strive to be culturally competent and family-centered in their approach to conceptual and measurement issues. Because of the need to generate new knowledge in this area, CHI PACC[®] programs further accept the responsibility to protect the rights of patient privacy and to understand and guard against any potential harm, including psychological burden, to families and patients who participate in ongoing research and/or evaluation activities.

Practice:

- R.E.1. The CHI PACC[®] program has a defined and timely research agenda, plan, and structure for implementation.
- R.E.2. The CHI PACC[®] program staff at all levels is educated to the importance and necessity of research, its different approaches and methods, and requirements for the protection of human subjects. CHI PACC[®] program staff also is encouraged to initiate and/or participate in research activities.
- R.E.3. The CHI PACC[®] program provides resources to support the research activities it undertakes.
- R.E.4. THE CHI PACC[®] program encourages research collaborations locally and nationally to expedite the process of generating new knowledge and establishing clinical consensus.
- R.E.5. The CHI PACC[®] program has an organized and effective way to facilitate communication and sharing of tools and knowledge to others who are providing comprehensive pediatric care, including palliative and end-of-life care.
- R.E.6. The scope of outcomes that are relevant to the quality of care in pediatric services include outcomes across the care continuum and extend to bereavement care. The focus of outcomes are broad and span patient and family satisfaction, quality of life, provider satisfaction, cost-effectiveness, clinical performance, and health systems change.
- R.E.7. The CHI PACC[®] program participates in national cross-site type evaluation studies as

needed and supports the collection of nationally-based data, criteria, and evaluation information over and above information needed for program specific goals.

- R.E.8. The CHI PACC[®] program has methods and procedures for monitoring, evaluating and improving its performance in meeting its most fundamental assumptions of access to a continuum of integrated disease management and palliative care from the time of diagnosis, with hope of cure, until the time of discharge from the program, as well as consistency of care across all settings of care and cost effectiveness.
- R.E.9. The CHI PACC[®] program has an organized, effective and consistent way in which professional and volunteer staff members evaluate the effectiveness and adequacy of its policies and procedures, outreach, services, programs, management, and governance.
- R.E.10. The CHI PACC[®] program has an organized, effective method by which primary care pediatricians, professionals in disease and treatment, and key staff members in other collaborative settings and/or programs of care evaluate the effectiveness of the CHI PACC[®] program, its operation and services.
- R.E.11. The CHI PACC[®] program provides all reports, data and documentation required by funders and constituents in a timely, accurate manner.
- R.E.12. The CHI PACC[®] program participates in all required activities which foster the development and expansion of the national CHI PACC[®] model.
- R.E.13. The CHI PACC[®] program has an up-to-date written program for program improvement and utilization review.

GOVERNANCE AND ADMINISTRATION

Principle:

The governance and administration of, or for the CHI PACC[®] program, establishes, supports, and develops the program as a priority to meet the needs of children/adolescents and families in the community and/or region it serves. Governance may be achieved through an independent Board of Directors or an Advisory Board.

Practice:

- G.A.1. The governance structure for the CHI PACC[®] program insures that its mission, vision, general policies, and range of services implement the national CHI PACC[®] program standards to meet the needs of children/adolescents with life-threatening conditions and the members of their families in the program's service area.

- G.A.2. The governance structure of the CHI PACC[®] program includes a broad representation of its service area, including diverse community representatives, professional and/or industry representatives, and children/adolescents and family members, while protecting against incurring conflicts of interest.
- G.A.3. The governance structure of the CHI PACC[®] program insures the integrity and functioning of the CHI PACC[®] program by providing the level of resources necessary to provide the level of care, mix of services, and range of collaboration needed to meet the needs of children/adolescents and families throughout its service area.
- G.A.4. The CHI PACC[®] program director is accountable to an appropriate institutional administrator or governance structure.
- G.A.5. The administration and organizational structure of the CHI PACC[®] program is adequate and appropriate for its mission, principal functions, goals and objectives, requirements for services, and size of program.
- G.A.6. The CHI PACC[®] program has suitable, adequate, appropriate space, work and service environments, equipment, supplies, security and safety systems, communication systems, and other essential resources.
- G.A.7. The governance and administration of the CHI PACC[®] program participates in the ongoing development, refinement, and positioning of the CHI PACC[®] model and vision of care for children/adolescents and their families.