

All clinicians have the responsibility to improve outcomes and provide person-centered care for people with serious illness—but many have not received the necessary training. Clinicians and health care organizations can use CAPC’s training recommendations as a skills-building roadmap.

Based on guidance from the National Consensus Project’s [Clinical Practice Guidelines for Quality Palliative Care](#), the recommendations cover four aspects of care:

1. Assessing the needs and concerns of pediatric patients and families
2. Strengthening the care team, patient, and family relationship, and understanding care goals
3. Managing pain and symptoms
4. Preventing crises and helping patients plan ahead

Training Recommendations by Discipline

- [Pediatric Physicians \(Pediatricians\)](#)
- [Pediatric Physician Assistants](#)
- [Pediatric Advanced Practice Registered Nurses](#)
- [Pediatric Registered Nurses](#)
- [Pediatric Social Workers](#)
- [Pediatric Chaplains](#)
- [Pediatric Psychologists](#)

Learn more at capc.org/training-recommendations-pediatrics

For Pediatric Physicians (Pediatricians)

Domain	Skills for All Pediatricians	Additional Skills for Pediatricians Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients¹ and Families²	<ul style="list-style-type: none"> • Know what palliative care is, and how and when to request a consult • Assess pediatric patients' physical, mental, and social well-being at all stages of disease using developmentally- and culturally-appropriate methods • Communicate with existing psychosocial and spiritual supports regarding patient and family needs • In the absence of available palliative care resources, know how to access appropriate psychosocial support structures 	<ul style="list-style-type: none"> • Recognize common sources of distress for pediatric patients with serious illness and/or complex needs • Perform a comprehensive assessment, using developmentally- and culturally-appropriate tools, that includes: <ul style="list-style-type: none"> ○ Social factors encompassing social determinants of health and family functioning ○ Polypharmacy ○ Care coordination ○ Emotional and spiritual distress ○ Physical symptom distress ○ Communication challenges for patients and families ○ Need for adaptive equipment and home care delivery supplies • Assess family readiness to anticipate, identify, and respond to changes in health status and needs
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Identify the pediatric patient's surrogate decision-maker(s), if not the parents • Support shared decision-making that is aligned with patients' and families' values and preferences; ensure that pediatric patients have a voice in the discussion, as developmentally appropriate • Identify how social determinants of health³ influence pediatric patients' decision-making, and deliver 	<ul style="list-style-type: none"> • Conduct skilled conversations with families (and pediatric patients as developmentally- and culturally appropriate) about what to expect and what matters specific to serious illness/complex care • Engage the interdisciplinary care team (IDT) as needed to provide developmentally- and culturally-appropriate education and support regarding coping with serious illness

¹ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

² Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

³ Defined as "the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries"

Domain	Skills for All Pediatricians	Additional Skills for Pediatricians Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<p>responsive, unbiased care matched to needs and priorities</p> <ul style="list-style-type: none"> Identify additional health care professionals who should be brought into the care team; support patients and families through care coordination across and among providers and sites of care, and help navigate health system barriers Document and disseminate goals of care and advance care plans in the medical record; or be familiar with advance care planning documents and know when it is appropriate to ask if these have been completed, and gain a copy of completed documents Document legal guardianship and custody preferences in the event of caregiver death plus attain copies of legal documents when patient does not have decision-making capacity Know when to consult specialty palliative care for complex decision-making Assess and address the psychosocial needs of siblings Provide continuity of general pediatric care, following families in a supportive role when subspecialists become the primary care team and/or after pediatric patients die; provide access to bereavement support for parents and siblings 	<ul style="list-style-type: none"> Conduct culturally-sensitive advance care planning conversations and complete advance directives, if desired; facilitate documentation sharing with extended care team Consider legal and ethical aspects of care, and be aware of how to consult pediatric ethics experts when needed Develop a basic understanding of pediatric hospice care, including concurrent care,⁴ and contact palliative care to assist with hospice enrollment when appropriate Identify pediatric patients who are eligible for hospice care and support them to make the decision whether to enroll As a member of the patient's IDT, anticipate and help navigate health system barriers alongside social worker and other integral team members With support from other members of the IDT, provide assistance in providing continuity, communication, and coordinating care across settings Assist families in creating clear plans for which clinical service or clinician to contact in case of specific symptoms, illness or emergency, and when to contact hospice if applicable Discuss what to expect during the dying process, including symptom management, and respond to the emotional needs of caregivers and family
Manage Pain and Symptoms	<ul style="list-style-type: none"> Using developmentally- and culturally-appropriate tools, assess and address the distress caused by common symptoms associated with serious illness 	<ul style="list-style-type: none"> Anticipate and address the full spectrum of potential symptoms related to specific serious illnesses or conditions, and their evolution over time, using

⁴ Provision in the *Affordable Care Act* that allows children with life-threatening health problems who are enrolled in Medicaid to get both curative treatment that focuses on curing a health condition and hospice care.

Domain	Skills for All Pediatricians	Additional Skills for Pediatricians Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Assess the feasibility and safety of the care plan with pediatric patients and families • Provide written response plans for emergencies or symptom escalation for pediatric patients and their families when appropriate • Identify pediatric patients who would benefit from a specialty pediatric palliative care consultation for complex or intractable symptoms • Assess for/understand the role of integrative therapies in pediatric patients' care plan • Conduct opioid risk assessment if prescribing opioids and know resources if concern emerges 	<p>developmentally-appropriate tools, including symptoms at end of life</p> <ul style="list-style-type: none"> • Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused, and culturally-congruent care • Provide multimodal pain or symptom treatment, along with child life, PT/OT, massage, and other integrative therapies • Understand limitations of pain and symptom assessment tools in pediatric patients with cognitive impairment • Recognize symptom co-occurrence and prioritize management of multiple, co-occurring symptoms • Empower pediatric patients and families with symptom management plans that provide flexibility and autonomy to allow for changing needs • Understand and practice safe opioid and other controlled substance prescribing and deploy clear processes to maintain patient and prescriber safety • Assess and reassess the benefits and burdens of polypharmacy, and deprescribe when appropriate
Prevent Crises and Plan Ahead	<ul style="list-style-type: none"> • Collaborate in planning to return to the community from non-home settings, with consideration for continuity of care across settings • Recognize non-physical sources of distress and refer patients to community-based palliative care, social work, behavioral health, and/or spiritual support • Assess functioning, including mental health status, of all family members and refer to mental health services as indicated • Recognize and respond to stressors on families' ability to care for the patient 	<ul style="list-style-type: none"> • Identify barriers to meeting pediatric patients' and families' needs and honoring their priorities, and discuss least restrictive alternatives • Assess for and develop a crisis intervention plan, including suicide prevention for all family members • Empower families with medication or technology/equipment titration plans that provide flexibility for illness management at home • Create emergency care plans, and contingencies for families' needs at home that include information about who to contact for specific needs

Domain	Skills for All Pediatricians	Additional Skills for Pediatricians Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Refer for a home safety and accessibility evaluation as needed • Confirm access to care plans developed in other domains; periodically revisit as circumstances change, including changes in child development stage, care setting, health status • Confirm that respite services are available, family knows how to access or how to refer families to these resources • Evaluate risks from polypharmacy and consider de-prescribing • Ensure training opportunities for family in use of technology and equipment in the home, and written back-up plans on how to get support for equipment failures/problems • Assist the family in developing a plan for identifying and responding to acute changes in status, including whom to contact (24/7) for escalation of care. Document and disseminate the plan in the medical record and other emergency notification systems • Ensure all documentation is provided to patient, family in their primary language 	<ul style="list-style-type: none"> • Identify community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and families • Assist with transitioning from inpatient to outpatient medication regimens, including medication reconciliation, route of delivery, deprescribing, and integrating pharmacists into the care • Review crisis plan as part of advance care planning discussions, ensure that proper documentation is in place and that families know whom to contact 24/7 in case of a crisis • Partner with IDT in identifying and engaging community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and caregivers • Identify processes for prioritizing transportation and access to reliable utilities in the event of outages

For Pediatric Physician Assistants

Domain	Skills for All Pediatric Physician Assistants	Additional Skills for Pediatric Physician Assistants Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients⁵ and Families⁶	<ul style="list-style-type: none"> • Know what palliative care is, and how and when to request a consult • Assess pediatric patients' physical, mental, social, and spiritual well-being at all stages of disease using developmentally- and culturally-appropriate methods • Communicate with existing psychosocial and spiritual supports regarding patient and family needs • In the absence of an available palliative care team, know how to access appropriate psychosocial support 	<ul style="list-style-type: none"> • Recognize common sources of distress for pediatric patients with serious illness and/or complex needs • Perform a comprehensive assessment, using developmentally- and culturally-appropriate tools, that includes: <ul style="list-style-type: none"> ○ Social factors encompassing social determinants of health and family functioning ○ Polypharmacy ○ Emotional and spiritual distress ○ Care coordination ○ Physical symptom distress ○ Communication challenges for patients and families ○ Need for adaptive equipment and home care delivery supplies • Assess family readiness to anticipate, identify, and respond to changes in health status and needs
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Identify pediatric patients' surrogate decision-maker(s), if not the parents • Conduct developmentally- and culturally-appropriate conversations with pediatric patients and families to understand what matters most to them • Support shared decision-making that is aligned with patients' and families' values and preferences; ensure that pediatric patients have a voice in the discussion, as developmentally appropriate 	<ul style="list-style-type: none"> • Conduct skilled conversations with families (and pediatric patients as developmentally- and culturally appropriate) about what to expect and what matters specific to serious illness/complex care • Engage the interdisciplinary care team (IDT) as needed to provide developmentally- and culturally-appropriate education and support regarding coping with serious illness • Conduct culturally-sensitive advance care planning conversations and complete advance directives if desired; facilitate documentation sharing with extended care team

⁵ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

⁶ Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

Domain	Skills for All Pediatric Physician Assistants	Additional Skills for Pediatric Physician Assistants Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Identify how social determinants of health⁷ influence pediatric patients' and families' decision-making in the context of a serious illness, and deliver responsive, unbiased care matched to needs and priorities • Identify additional health care professionals who should be brought into the care team; support patients and families through care coordination across and among providers and sites of care, and help navigate health system barriers • Document and disseminate goals of care and advance care plans in the medical record; or be familiar with advance care planning documents and know when it is appropriate to ask if these have been completed, and gain a copy of completed documents • Know when to consult specialty palliative care for complex decision-making • Assess and address the psychosocial needs of siblings • Provide continuity of general pediatric care, following families in a supportive role when subspecialists become the primary care team and/or after pediatric patients die; provide access to bereavement support for parents and siblings 	<ul style="list-style-type: none"> • Consider legal and ethical aspects of care and be aware of how to consult pediatric ethics experts when needed • Develop a basic understanding of pediatric hospice care, including concurrent care,⁸ and contact palliative care to assist with hospice enrollment when appropriate • Identify pediatric patients who are eligible for hospice care and support them to make the decision whether to enroll; anticipate and help navigate health system barriers • With support from other members of the IDT, provide assistance in providing continuity, communication, and coordinating care across settings • Assist families in creating clear plans for which clinical service or clinician to contact in case of specific symptoms, illness, or emergency, and when to contact hospice if applicable • Discuss what to expect during the dying process, including symptom management, and respond to the emotional needs of caregivers and family
Manage Pain and Symptoms	<ul style="list-style-type: none"> • Using developmentally- and culturally-appropriate tools, assess and address the distress caused by common symptoms associated with serious illness 	<ul style="list-style-type: none"> • Anticipate and address the full spectrum of symptoms related to specific serious illnesses or conditions along the trajectory using

⁷ Defined as “the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries”

⁸ Provision in the *Affordable Care Act* that allows children with life-threatening health problems who are enrolled in Medicaid to get both curative treatment that focuses on curing a health condition and hospice care.

Domain	Skills for All Pediatric Physician Assistants	Additional Skills for Pediatric Physician Assistants Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Assess the feasibility and safety of the care plan with pediatric patients and families • Provide written response plans for emergencies or symptom escalation for pediatric patients and their families when appropriate • Identify pediatric patients who would benefit from a specialty pediatric palliative care consult for complex or intractable symptoms • Assess for/understand the role of integrative therapies in pediatric patients' care plan • Conduct opioid risk assessment if prescribing opioids 	<p>developmentally appropriate tools, including symptoms at end of life</p> <ul style="list-style-type: none"> • Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused, and culturally-congruent care • Provide multimodal pain or symptom treatment, along with child life, PT/OT, massage, and other ancillary services • Understand limitations of pain and symptom assessment tools in pediatric patients with cognitive impairment • Recognize symptom co-occurrence and prioritize management of multiple, co-occurring symptoms • Empower pediatric patients and families with symptom management plans that provide flexibility and autonomy to allow for changing needs • Understand and practice safe opioid and other controlled substance prescribing and deploy clear processes to maintain patient and prescriber safety • Assess and reassess the benefits and burdens of polypharmacy, and deprescribe when appropriate
Prevent Crises and Plan Ahead	<ul style="list-style-type: none"> • Collaborate in planning to return to the community from non-home settings, with consideration for continuity of care across settings • Recognize non-physical sources of distress, and collaborate with community-based palliative care, social work, behavioral health, and/or spiritual support • Assess functioning, including mental health status, of all family members • Recognize and respond to stressors on family's ability to care for the patient 	<ul style="list-style-type: none"> • Identify barriers to meeting pediatric patients' and family needs and honoring their priorities, and discuss least restrictive alternatives • Assess for and develop a crisis intervention plan, including suicide prevention for all family members • Empower families with medication or technology/equipment titration plans that provide flexibility for illness management at home • Create emergency care plans and contingencies for families' needs at home that include information about who to contact for specific needs

Domain	Skills for All Pediatric Physician Assistants	Additional Skills for Pediatric Physician Assistants Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Refer for a home safety and accessibility evaluation as needed • Confirm access to care plans developed in other domains; periodically revisit as circumstances change, including changes in child development stage, care setting, health status • Confirm that respite services are available and that the family knows how to access • Evaluate risks from polypharmacy and consider deprescribing • Ensure training opportunities for family in use of technology and equipment in the home, and written back-up plans on how to get support for equipment failures/problems • Assist the family in developing a plan for identifying and responding to acute changes in status, including whom to contact (24/7) for escalation of care. Document and disseminate the plan in the medical record and other emergency notification systems 	<ul style="list-style-type: none"> • Identify community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and families • Assist with transitioning from inpatient to outpatient medication regimens, including medication reconciliation, route of delivery, deprescribing, and integrating pharmacists into the care • Review crisis plan as part of advance care planning discussions, ensure that proper documentation is in place and that families know whom to contact 24/7 in case of crisis • Partner with IDT in identifying and engaging community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and caregivers

For Pediatric Advanced Practice Registered Nurses

Domain	Skills for All Pediatric APRNs (Nurse Practitioners and CNSs)	Additional Skills for Pediatric APRNs Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients⁹ and Families¹⁰	<ul style="list-style-type: none"> • Know what palliative care is, how and when to request a consult, and how and when to refer for both inpatient and outpatient palliative care • Assess pediatric patients' physical, mental, social, and spiritual well-being at all stages of disease using developmentally- and culturally-appropriate methods • Communicate and connect with existing psychosocial and spiritual supports regarding patient and family needs • In the absence of an available palliative care team, know how to access appropriate psychosocial support structures 	<ul style="list-style-type: none"> • Recognize common sources of distress for pediatric patients with serious illness and/or complex needs • Perform a comprehensive assessment, using developmentally- and culturally-appropriate tools, that includes: <ul style="list-style-type: none"> ○ Social factors encompassing social determinants of health and family functioning ○ Polypharmacy ○ Emotional and spiritual distress ○ Care coordination ○ Physical symptom distress ○ Communication challenges for patients and families ○ Need for adaptive equipment and home care delivery supplies • Assess family readiness to anticipate, identify, and respond to changes in health status and needs
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Identify pediatric patients' surrogate decision-maker(s), if not the parents • Conduct developmentally- and culturally-appropriate conversations with pediatric patients and families to understand what matters most to them • Support shared decision-making that is aligned with patients' and families' values and preferences; ensure that pediatric patients have a voice in the discussion, as developmentally appropriate 	<ul style="list-style-type: none"> • Conduct skilled conversations with families (and pediatric patients as developmentally- and culturally appropriate) about what to expect and matters specific to serious illness/complex care • Engage the interdisciplinary care team (IDT) as needed to provide developmentally- and culturally-appropriate education and support regarding coping with serious illness • Conduct culturally-sensitive advance care planning conversations and complete advance directives if desired; facilitate documentation sharing with extended care team

⁹ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

¹⁰ Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

Domain	Skills for All Pediatric APRNs (Nurse Practitioners and CNSs)	Additional Skills for Pediatric APRNs Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> Identify how social determinants of health¹¹ influence pediatric patients' and families' decision-making in the context of a serious illness, and deliver responsive, unbiased care matched to needs and priorities Identify additional health care professionals who should be brought into the care team; support patients and families through care coordination across and among providers and sites of care, and help navigate health system barriers Document and disseminate goals of care and advance care plans in the medical record (including EMR); or be familiar with advance care planning documents and know when it is appropriate to ask if these have been completed, and gain a copy of completed documents Know when to consult specialty palliative care for complex decision-making Assess and address the psychosocial needs of siblings Provide continuity of general pediatric care, partner with subspecialists throughout disease and bereavement; provide bereavement support for parents and siblings 	<ul style="list-style-type: none"> Consider legal and ethical aspects of care and be aware of how to consult pediatric ethics experts when needed Develop a basic understanding of pediatric hospice care, including concurrent care,¹² and contact palliative care to assist with hospice enrollment when appropriate Identify pediatric patients who are eligible for hospice care, and support them to make the decision whether to enroll; anticipate and help navigate health system barriers With support from other members of the IDT, provide assistance in providing continuity, communication, and coordinating care across settings Assist families in creating clear plans for which clinical service or clinician to contact in case of specific symptoms, illness, or emergency, and when to contact hospice if applicable Discuss what to expect during the dying process, including symptom management, and respond to the emotional needs of caregivers and family
Manage Pain and Symptoms	<ul style="list-style-type: none"> Using developmentally- and culturally-appropriate tools, assess and address the distress caused by common symptoms associated with serious illness Assess the feasibility and safety of the care plan with pediatric patients and families 	<ul style="list-style-type: none"> Anticipate and address the full spectrum of symptoms related to specific serious illnesses or conditions along the trajectory using developmentally appropriate tools, including symptoms at end of life

¹¹ Defined as “the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries”

¹² Provision in the *Affordable Care Act* that allows children with life-threatening health problems who are enrolled in Medicaid to get both curative treatment that focuses on curing a health condition and hospice care.

Domain	Skills for All Pediatric APRNs (Nurse Practitioners and CNSs)	Additional Skills for Pediatric APRNs Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Provide written response plans for emergencies or symptom escalation for pediatric patients and their families when appropriate • Identify pediatric patients who would benefit from a specialty pediatric palliative care consult for complex or intractable symptoms • Assess for/understand the role of integrative therapies in pediatric patients' care plan • Conduct opioid risk assessment if prescribing opioids 	<ul style="list-style-type: none"> • Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused, and culturally-congruent care • Provide multimodal pain or symptom treatment, along with child life, PT/OT, massage, and other ancillary services • Understand limitations of pain and symptom assessment tools in pediatric patients with cognitive impairment • Recognize symptom co-occurrence and prioritize management of multiple, co-occurring symptoms • Empower pediatric patients and families with symptom management plans that provide flexibility and autonomy to allow for changing needs • Understand and practice safe opioid and other controlled substance prescribing and deploy with clear processes to maintain patient and prescriber safety • Assess and reassess the benefits and burdens of polypharmacy, and deprescribe when appropriate
Prevent Crises and Plan Ahead	<ul style="list-style-type: none"> • Collaborate in planning to return to the community from non-home settings, with consideration for continuity of care across settings • Recognize non-physical sources of distress, and collaborate with community-based palliative care, social work, behavioral health, and/or spiritual support • Assess functioning, including mental health status, of all family members • Recognize and respond to stressors on family's ability to care for the patient • Refer for a home safety and accessibility evaluation as needed 	<ul style="list-style-type: none"> • Identify barriers in the home/community environment to meeting pediatric patient and family needs and honoring their priorities, and discuss least restrictive alternatives • Assess for and develop a crisis intervention plan, including suicide prevention for all family members • Empower families with medication or technology/equipment titration plans that provide flexibility for illness management at home • Create emergency care plans, and contingencies for families' needs at home that include information about who to contact for specific needs

Domain	Skills for All Pediatric APRNs (Nurse Practitioners and CNSs)	Additional Skills for Pediatric APRNs Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Confirm access to care plans developed in other domains; periodically revisit as circumstances change, including changes in child development stage, care setting, health status • Confirm that respite services are available, family knows how to access • Evaluate risks from polypharmacy and consider deprescribing • Ensure training opportunities for family in use of technology and equipment in the home, and written back-up plans on how to get support for equipment failures/problems • Assist the family in developing a plan for identifying and responding to acute changes in status, including whom to contact (24/7) for escalation of care. Document and disseminate the plan in the medical record and other emergency notification systems 	<ul style="list-style-type: none"> • Identify community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and families • Assist with transitioning from inpatient to outpatient medication regimens, including medication reconciliation, route of delivery, deprescribing, and integrating pharmacists into the care • Review crisis plan as part of advance care planning discussions, ensure that proper documentation is in place and that families know whom to contact 24/7 in case of a crisis • Partner with IDT in identifying and engaging community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and caregivers

For Pediatric Registered Nurses

Domain	Skills for All Pediatric Registered Nurses	Additional Skills for Pediatric Registered Nurses Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients¹³ and Families¹⁴	<ul style="list-style-type: none"> • Know what palliative care is, and how and when to request a consult • Assess pediatric patients' physical, mental, social, and spiritual well-being at all stages of disease using developmentally- and culturally-appropriate methods • Screen for common symptoms and advocate with team for effective management • Screen for polypharmacy • Screen for communication barriers for patients and families 	<ul style="list-style-type: none"> • Recognize common sources of distress for pediatric patients with serious illness and/or complex needs • Collect data using developmentally- and culturally-appropriate tools, that include: <ul style="list-style-type: none"> ○ Social factors encompassing social determinants of health and family functioning ○ Care coordination ○ Emotional and spiritual distress ○ Need for adaptive equipment and home care delivery supplies
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Identify pediatric patients' surrogate decision-maker(s), if not the parents • Support shared decision-making that is aligned with patients' and families' values and preferences; ensure that pediatric patients have a voice in the discussion, as developmentally appropriate • Identify how social determinants of health¹⁵ influence pediatric patients' and their families' decision-making in the context of a serious illness and deliver responsive, unbiased care matched to needs and priorities • Identify patients who are eligible for hospice, including concurrent care,¹⁶ and support them to 	<ul style="list-style-type: none"> • Elicit goals, values, preferences, and concerns of families and pediatric patients, provided this approach is culturally acceptable and aligned with the family system • Facilitate and participate in conversations with patients and families about what to expect, and advocate on behalf of patients' values and preferences • Balance autonomy of pediatric patients in the context of serious illness treatment with respect for decision-maker(s) choice for communication with pediatric patients • Support care coordination across the health care continuum

¹³ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

¹⁴ Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

¹⁵ Defined as "the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries"

¹⁶ Provision in the *Affordable Care Act* that allows children with life-threatening health problems who are enrolled in Medicaid to get both curative treatment that focuses on curing a health condition and hospice care.

Domain	Skills for All Pediatric Registered Nurses	Additional Skills for Pediatric Registered Nurses Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<p>make the decision whether to enroll; anticipate and help navigate health system barriers</p>	<ul style="list-style-type: none"> Participate in culturally-sensitive advance care planning conversations and complete advance directives if desired; facilitate documentation sharing with extended care team
<p>Manage Pain and Symptoms</p>	<ul style="list-style-type: none"> Manage the implementation of treatments for common symptoms associated with serious illness Assess the feasibility and safety of the care plan with pediatric patients and families Identify pediatric patients who would benefit from a specialty pediatric palliative care consult for complex or intractable symptoms, and discuss with the lead provider, care team, community partners, and/or any other provider in the patient’s “network” 	<ul style="list-style-type: none"> Anticipate the full spectrum of symptoms related to specific serious illnesses or conditions along the trajectory Consult with or refer patients to palliative care specialists when implementation of first-line treatments according to the palliative care plan have not been effective at managing symptoms; be familiar with alternative and integrative therapies to discuss with the care team Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused, and culturally-congruent care Assist with ensuring that care plans are communicated across the continuum of a patient’s care Assist with education and training for inpatient, home health, and hospice nursing personnel to facilitate their comfort level in the provision of high-quality care for pediatric patients
<p>Prevent Crises and Plan Ahead</p>	<ul style="list-style-type: none"> Recognize non-physical sources of distress, and recommend community-based palliative care, social work, behavioral health, and/or spiritual support Assess function and refer for a home safety accessibility evaluation as needed Screen for polypharmacy and work with team to consider deprescribing 	<ul style="list-style-type: none"> Identify community resources that can support pediatric patients living with serious or complex illness, and their siblings and caregivers Identify barriers to meeting pediatric patients’ and family needs and honoring their priorities, and discuss least restrictive alternatives

For Pediatric Social Workers

Domain	Skills for All Pediatric Social Workers	Advanced Skills for Pediatric Social Workers Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients¹⁷ and Families¹⁸	<ul style="list-style-type: none"> • Know what palliative care is, and how and when to request a consult • Assess pediatric patients' physical, mental, social, and spiritual well-being at all stages of disease using developmentally- and culturally-appropriate methods • Assess caregiving needs and resources 	<ul style="list-style-type: none"> • Recognize common sources of distress for pediatric patients with serious illness and/or complex needs • Perform a comprehensive assessment using developmentally- and culturally-appropriate tools that includes: <ul style="list-style-type: none"> ○ Social factors encompassing social determinants of health and family functioning ○ Care coordination ○ Emotional and spiritual distress ○ Physical symptom distress ○ Communication challenges for patients and families ○ Need for adaptive equipment and home care delivery of supplies ○ Pediatric patient education
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Identify pediatric patients' surrogate decision-maker(s), if not the parents • Conduct developmentally- and culturally-appropriate conversations with pediatric patients and families to understand what matters most to them • Support shared decision-making that is aligned with patients' and families' values and preferences; ensure that pediatric patients have a voice in the discussion, as developmentally appropriate • Ensure siblings' needs are addressed through the plan of care • Conduct culturally-sensitive advance care planning conversations and complete advance directives, if 	<ul style="list-style-type: none"> • Elicit goals, values, preferences and concerns of families and pediatric patients, provided this approach is culturally acceptable and aligned with the family system • Balance autonomy of pediatric patients in the context of serious illness with respect for families' choice for communication with the pediatric patients • Conduct skilled conversations with patients and families about matters specific to serious illness/complex care • Provide developmentally- and culturally-appropriate psychoeducation and clinical interventions to pediatric patients and family/caregivers regarding coping with serious illness

¹⁷ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

¹⁸ Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

Domain	Skills for All Pediatric Social Workers	Advanced Skills for Pediatric Social Workers Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<p>desired; facilitate documentation sharing with extended care team</p> <ul style="list-style-type: none"> Identify how social determinants of health¹⁹ influence pediatric patients' and families' decision-making in the context of a serious illness, and deliver responsive, unbiased care matched to needs and priorities Identify patients who are eligible for hospice care, including concurrent care,²⁰ and support them as they make the decision whether to enroll; anticipate and help navigate health system barriers 	<ul style="list-style-type: none"> Coordinate care across the health care continuum
Manage Pain and Symptoms	<ul style="list-style-type: none"> Using developmentally- and culturally-appropriate tools, assess and address the distress caused by common symptoms associated with serious illness Assess the feasibility and safety of the care plan with pediatric patients and families Assess and identify cognitive impairment Identify pediatric patients who would benefit from a specialty pediatric palliative care consult for complex or intractable symptoms, and refer or discuss with the lead provider, care team, community partners, and/or any other provider in the patient's "network" 	<ul style="list-style-type: none"> Anticipate and address the full spectrum of symptoms related to specific serious illnesses or conditions along the trajectory Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused, and culturally-congruent care Assess for/understand the role of integrative therapies in pediatric patients' care plan and be prepared to advocate on behalf of the patient
Prevent Crises and Plan Ahead	<ul style="list-style-type: none"> Collaborate in planning to return to the community from non-home settings, with consideration for continuity of care across settings When necessary, advocate for resources and care on behalf of pediatric patients and families and/or empower them to play a role in this advocacy 	<ul style="list-style-type: none"> Identify community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and caregivers Assist with obtaining access to the least restrictive educational environment, advocate for medication and resuscitation needs in school settings

¹⁹ Defined as "the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries"

²⁰ Provision in the *Affordable Care Act* that allows children with life-threatening health problems who are enrolled in Medicaid to get both curative treatment that focuses on curing a health condition and hospice care.

Domain	Skills for All Pediatric Social Workers	Advanced Skills for Pediatric Social Workers Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<ul style="list-style-type: none"> • Recognize non-physical sources of distress, and collaborate with community-based palliative care, behavioral health, and/or spiritual support • Assess functioning, including mental health status of all family members • Refer patients for a home safety accessibility evaluation as needed • Work with the patient (as appropriate) and caregivers to ensure medication safety in the home • Revisit hospice eligibility as appropriate 	<ul style="list-style-type: none"> • Identify barriers to meeting pediatric patients' and families' needs and honoring their priorities, and discuss least restrictive alternatives • Assess for and develop a crisis intervention plan, including suicide prevention for all family members • In the case of terminal illness, collaborate with members of the care team to prepare pediatric patients and their family members for expected course of decline and provide psychoeducation about the range of normative emotional reactions • Provide guidance on anticipatory grief, and connect family with grief/bereavement resources as needed

For Pediatric Chaplains

Domain	Skills for All Pediatric Chaplains	Additional Skills for Pediatric Chaplains Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients²¹ and Families²²	<ul style="list-style-type: none"> • Know what palliative care is, and how and when to request a consult; if a specialty team isn't available, serve as the informal facilitator for addressing patient and family palliative care needs through the treating team • Assess pediatric patients' spiritual, religious, emotional and relational needs and resources at all stages of disease using developmentally- and culturally-appropriate methods 	<ul style="list-style-type: none"> • Explore the emotional and spiritual dimensions of common sources of distress for pediatric patients with serious illness and/or complex needs • Perform an assessment, using developmentally- and culturally-appropriate tools, that includes: <ul style="list-style-type: none"> ○ Social/spiritual factors encompassing social determinants of health and family functioning ○ Emotional and spiritual distress and how they might manifest as physical distress ○ Communication challenges for patient and family ○ Protective factors
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Conduct developmentally- and culturally-appropriate conversations with pediatric patients and families to understand what matters most to them; elicit goals, values, preferences, and concerns of families and patients • Aid in identifying how social determinants of health²³ influence pediatric patients' and families' decision-making in the context of a serious illness, and deliver responsive, unbiased care matched to needs and priorities • Conduct conversations with pediatric patients and families about core matters specific to serious illness/complex care • Support shared decision-making that is aligned with patients' and families' values and preferences; 	<ul style="list-style-type: none"> • Provide developmentally- and culturally-appropriate education and support regarding coping with serious illness • In collaboration with the medical team, conduct culturally-sensitive advance care planning discussions and complete advance directives if desired; facilitate documentation sharing with extended care team • Conduct skilled conversations with pediatric patients and families about difficult matters specific to serious illness/complex care • Conduct skilled conversations/assist team members with navigating grief and team conflict

²¹ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

²² Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

²³ Defined as "the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries"

Domain	Skills for All Pediatric Chaplains	Additional Skills for Pediatric Chaplains Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<p>ensure that pediatric patients have a voice in the discussion, as developmentally appropriate</p> <ul style="list-style-type: none"> • Bring team, patients, and families into greater alignment on achievable goals for care; incorporate values into the treatment plan and goals of care • Liaise with community-based spiritual support as important to the family 	
Manage Pain and Symptoms	<ul style="list-style-type: none"> • Using developmentally- and culturally-appropriate tools, assess and address the spiritual/existential underpinnings of distress caused by common symptoms associated with serious illness, and alert the care team to symptom burden • Be aware of referrals for complex issues of cognitive impairment, intractable symptoms, and safety • Process grief, support meaning-making 	<ul style="list-style-type: none"> • Anticipate and address the spiritual/existential underpinnings of complex symptoms related to specific serious illnesses or conditions along the trajectory, and support meaning-making, hope, belongingness • Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused and culturally-congruent care • Identify non-pharmacological and patient-specific interventions for coping with distress, and communicate with the team
Prevent Crises and Plan Ahead	<ul style="list-style-type: none"> • Collaborate in developing and implementing plans to support areas such as independent functioning or anticipatory grief; support and build positive coping mechanisms • Identify community resources that can support pediatric patients living with serious illness and/or complex needs and their siblings and families • Communicate with community clergy and/or other resources to ensure continuity of spiritual care • Support continuity of care across care settings • Aid in identification of bereavement services as needed 	<ul style="list-style-type: none"> • Provide spiritual support to families and pediatric patients, and connect family with resources as needed • In the case of terminal illness, provide spiritual support in the range of emotional reactions related to the dying process

For Pediatric Psychologists

Domain	Skills for All Pediatric Psychologists	Additional Skills for Pediatric Psychologists Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
Assess the Needs and Concerns of Pediatric Patients²⁴ and Families²⁵	<ul style="list-style-type: none"> • Know what palliative care is (and the role of psychologists in providing that care), and how and when to request a consult • Assess pediatric patient's physical, mental, social, and spiritual well-being at all stages of disease using developmentally- and culturally-appropriate methods • Assess parent mental health as appropriate, determine if additional services are needed (either provided directly or through referral) 	<ul style="list-style-type: none"> • Recognize common sources of distress for pediatric patients with serious illness and/or complex needs • Perform a comprehensive assessment, using developmentally- and culturally-appropriate tools that includes: <ul style="list-style-type: none"> ○ Social factors encompassing social determinants of health and family functioning ○ Coping: family strengths, strategies, resiliency factors, risk factors, including adverse childhood events ○ Emotional and spiritual distress ○ Mental health history ○ Physical symptom distress ○ Communication challenges for patients and families ○ Patient and caregiver medical understanding and factors affecting understanding (e.g., learning and/or developmental concerns) ○ History of and barriers to adherence ○ Pediatric patient education circumstances
Strengthen the Care Team, Patient, and Family Relationship, and Understand Care Goals	<ul style="list-style-type: none"> • Determine patient's preference for and ability to participate in decision-making using knowledge of socioemotional and cognitive development and direct patient discussion/assessment • Identify pediatric patients' surrogate decision-maker(s), if not the parents • Conduct developmentally- and culturally-appropriate conversations with pediatric patients 	<ul style="list-style-type: none"> • Conduct skilled conversations with pediatric patients and families, using developmentally appropriate language, about matters specific to serious illness/complex care • Conduct culturally-sensitive advance care planning conversations if desired; facilitate sharing of documentation with the care team

²⁴ Operationally defined to include neonates, perinates, infants, children, adolescents, and young adults.

²⁵ Operationally defined to include the adult(s) in the pediatric patient's support system that oversee and/or contribute to the patient's care (including parents and other caregivers who may or may not be related by blood)

Domain	Skills for All Pediatric Psychologists	Additional Skills for Pediatric Psychologists Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
	<p>and families to understand what matters most to them</p> <ul style="list-style-type: none"> • Support shared decision-making that is aligned with patients’ and families’ values and preferences; ensure that pediatric patients have a voice in that discussion as developmentally appropriate • Identify family barriers to having discussions about these topics and help facilitate conversations between youth and their caregivers to align preferences • Identify how social determinants of health influence²⁶ pediatric patients’ and families’ decision-making in the context of a serious illness, and deliver responsive, unbiased care matched to needs and priorities • Provide developmentally- and culturally-appropriate education regarding coping with serious illness 	<ul style="list-style-type: none"> • Identify patients who are amenable to hospice, including concurrent care,²⁷ and support them to make the decision whether to enroll; anticipate and help navigate health system barriers
Manage Pain and Symptoms	<ul style="list-style-type: none"> • Using developmentally- and culturally-appropriate tools, assess and address the distress caused by common symptoms associated with serious illness • Identify psychological and behavioral contributors to pediatric patients’ symptom presentations • Assess the feasibility and safety of the care plan with pediatric patients and families 	<ul style="list-style-type: none"> • Anticipate and address the full spectrum of symptoms related to specific serious illnesses or conditions along the disease trajectory • Develop the treatment plan to incorporate the values, meaning, and priorities of pediatric patients and family systems, including siblings, to provide person-centered, family-focused, and culturally-congruent care • Identify pediatric patients who would benefit from a specialty palliative care consult for complex or intractable symptoms, and refer or discuss with the care team

²⁶ Defined as “the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries”

²⁷ Provision in the *Affordable Care Act* that allows children with life-threatening health problems who are enrolled in Medicaid to get both curative treatment that focuses on curing a health condition and hospice care.

Domain	Skills for All Pediatric Psychologists	Additional Skills for Pediatric Psychologists Who Focus Primarily on Supporting Pediatric Patients with Serious Illness and/or Complex Needs
		<ul style="list-style-type: none"> Recognize and honor cultural influences on death and dying; facilitate incorporation of faith leaders and traditions as desired by families Understand grief in pediatric patients and families
Prevent Crises and Plan Ahead	<ul style="list-style-type: none"> Collaborate in planning to return to the community from non-home settings Identify pediatric patient and family concerns about managing symptoms at home, and proactively generate a symptom management plan Recognize non-physical sources of distress, and collaborate with community psychosocial colleagues to provide support when needed 	<ul style="list-style-type: none"> Identify community resources that can support pediatric patients living with serious illness and/or complex needs, and their siblings and family Assist with obtaining access to the least restrictive educational environment, advocate for medication and resuscitation needs in school settings Identify barriers to meeting pediatric patients' and families' needs and honoring their priorities Assess for and develop a crisis intervention plan, including suicide prevention for all family members In the case of terminal illness, collaborate with members of the care team to prepare pediatric patients and their family members for expected course of decline, and provide psychoeducation about the range of normative emotional reactions