

***Sustainability in Pediatric Palliative
and Hospice Care***

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Pediatric Palliative and Hospice Care

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Issue Topic: Sustainability

Welcome to the 66th issue of our Pediatric e-Journal. The impetus for this issue came from our realization that in three decades or so, the ChiPPS Newsletter, then the ChiPPS e-Journal, and now the NHPCO Pediatric e-Journal, has never had an issue focusing on this topic. Why? We think that several factors have led to this. First, in the early days, there simply weren't enough pediatric palliative care (PPC) or pediatric hospice programs to make any generalizations. Second, there are still many very different ways that programs with varying foci sustain themselves. Thirdly, sustainability isn't a very warm and fuzzy topic. Who likes to think of the grubby realities of MONEY in these noble causes? Yet, supporting the very existence of our programs is crucial to providing palliative and hospice care to children/adolescents and their caregivers. And, as we continued to develop this issue, we increasingly realized sustainability can mean many things to the many different types of programs that have been developed in pediatric palliative and hospice care. As contributors responded to our invitation to contribute to this issue and as their contributions reached us, we learned more about the implications of this subject matter. So now we can share a full issue devoted to the subject of sustainability in the hope that it will encourage every one of our readers to reflect more and discuss among ourselves this important aspect of being able to deliver robust and effective pediatric palliative and hospice care.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. **Chuck Corr is our Senior Editor.** Archived issues of this publication are available at www.nhpc.org/pediatrics.

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics like bereavement, sibling support, and standards for our remaining three issues in 2022. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

Produced by the Pediatric e-Journal Workgroup

- Charles A. Corr, PhD, Lacey, WA; Senior Editor
- Deborah Fisher, PhD, RN, PPCNP-BC, CHPPN, PANDA Palliative Care Nurse Practitioner, Children's National Hospital, Washington, DC
- Ann Fitzsimons, BS, MBA, Executive Director, here4U, Inc., Farmington Hills, MI

- Marta Friedman, LCSW, ACHP-SW, JD, Social Worker/Bereavement Coordinator, Complex Pain and Palliative Care Program (PACT Team), UCSF Benioff Children's Hospital, Oakland, CA
- Michelle Goldbach, Administrator/Director of Clinical Operations, Kindred Hospice, San Diego, CA
- Betsy Hawley, MA, Executive Director, Pediatric Palliative Care Coalition, Pittsburgh, PA
- Melissa Hunt, PharmD, Pediatric Clinical Pharmacist, Optum Hospice Pharmacy Services, O'Fallon, MO
- Nathan Ionascu, MD, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY
- Jennifer Mangers, MS, CCLS, Pediatric Program Manager, JourneyCare, Barrington, IL
- Jessica Sturgeon, MT-BC, Music Therapist, Seasons Hospice and Palliative Care, Middlebury, CT
- Suzanne Toce, MD, Retired Neonatologist, Gundersen Health System, La Crosse, WI; Co-Chair
- Christy Torkildson, RN, PHN, PhD, FPCN, Lead, MSN-Public Health Nursing Program, College of Nursing and Health Care Professions, Grand Canyon University, Phoenix, AZ; Co-Chair

Issue #66: Sustainability

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The Key to Building a Solid House Starts with the Foundation

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Tracy Leonard-Warner, MHI, MT-BC, and Susan Kricun

"One of the keys to Ryan House's success, initially, was the support it received in its first years—way before construction began...In 2005, five years before it opened its doors to the public, Ryan House began raising money. In that time, more than 4,000 gifts were given ranging from \$5 to \$250,000 by community supporters and corporations." Since Ryan House opened its doors nearly 12 years ago and began offering services, it has sought support from its community in ways described in this article.

Is a Community-Based Pediatric Hospice Program Sustainable?

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Holly Davis, MS, APRN

This article describes "three pillars for building a sustainable pediatric hospice program." They are: (1) Concurrent Care for Children; (2) State Coalitions; and (3) Organizational Assessment. The article concludes: "These pillars are basic building blocks to a sustainable community-based pediatric hospice program. Checking these items off your list will get you moving in the right direction for long-term success."

How to Sustain a Pediatric Palliative Care Program in the Community

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Kristen Eisenman, MD, Kimberly Statler Bennett, MD, MPH, and Susan Finke, RN, CHPN

"Footprints Children's Services is a community-based program of The Denver Hospice which has provided seamless care from diagnosis through treatment, from palliative care through hospice care, and from anticipatory grief counseling through bereavement for over 40 years." In this article, the authors describe the services provided by their program and the efforts they have made to sustain it, both financially and in other ways over the years.

PANDAS: How to Avoid the Endangered Species List, OR, Sustainability of an Inpatient Pediatric Palliative Care Team

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Deborah Fisher, PhD, RN, PPCNP-BC, CHPPN

"For the past 10 years, the Pediatric Advanced Needs Assessment team (PANDA) has grown

and thrived despite an earlier failed attempt to populate the habitat of a National Children's Hospital in 2005." What is this program doing differently now? Financially, it draws on three resources: (1) insurance billing; (2) philanthropy; and (3) organizational support. Beyond that, it builds links to other programs that depend on PANDA and keeps valuable metrics by joining the Pediatric Palliative Improvement Network and the Palliative Care Quality Collaborative.

Sustaining a Thriving Pediatric Palliative Care Program: FootprintsSM p. 17

Aimee Roddy, RN, MSN, CPNP-PC, and Katheryne Amba, PhD, DNP, CCRN, ACNP-BC

This article describes a hospital-based pediatric palliative care program in St. Louis, MO. Interestingly, the Co-Chair of this e-Journal's workgroup, Dr. Suzanne Toce, was among those who worked to initiate this program nearly 25 years ago. Now this article identifies several factors that have enabled the program to be sustained and to thrive.

Keys and Importance of Sustainable Pediatric Program Development: Lessons from Nevada p. 22

Angela Berg, DNP, APRN, CPNP

This article focuses on what is involved in developing a pediatric program under the concurrent care model: relationships, education, and continuous quality improvement, as well as a note on risks to sustainability.

Sustainability of Programs for Children and Families in Michigan p. 26

Elizabeth Rocha, RN, BSN, CHPPN

In this article, the author describes the Jo Elyn Nyman Anchors Programs for Children in Michigan, which includes a perinatal, a pre-hospice, and a formal hospice program for terminally ill pediatric patients and their families. These specialized programs depend mainly on donations to continue to offer their services.

Walking Home: A 25-Year Journey at Canuck Place Children's Hospice p. 28

Debbie Butt

Upon its inception, Canuck Place was the first free-standing children's hospice in North America. This article describes the robust services now offered by Canuck Place, growing from early donations and the support of the Vancouver Canucks hockey team. Quotations from and pictures of some of those who have been involved in this program testify to its inspiring growth and services.

Engaging Organizational Leadership in Advancing Sustainability for Pediatric Palliative and Hospice Care Programs p. 32

Stacy F. Orloff, Ed.D., LCSW, ACHP-SW

This author has extensive experience ranging from being a front-line social worker to becoming a senior executive supporting community-based pediatric palliative and hospice care programs. In this article, she suggests that "The missing component [in sustainability discussions for pediatric programs] is representation from organizational administrative leadership." Drawing on her own experience, she suggests some ideas for engaging administrative leaders in discussing sustainability of pediatric programs.

Sustainability of Self and Staff p. 34

Jessica Sturgeon, MT-BC, HPMT

This article begins by reminding us of the impact of the COVID-19 pandemic on health care workers and the negative trajectory it has often created. She then asks, "How do we as a health care community alter this trajectory to better sustain the passion, the staff, and the work itself?" Her answers are threefold:

listen to yourself, your peers, and your communities as they articulate their needs; “integrate better practices to highlight the accomplishments and hard work continually being done during this unprecedented time;” and provide “better supports for mental health to all health care staff.” Sustainability isn’t just about financial support; it must include appropriate support for those who care for others.

Sustainability and Statewide Pediatric Palliative and Hospice Care Coalitions

p. 37

Betsy Hawley, MA

This article reports data from a recent survey of statewide pediatric palliative and hospice care coalitions. The survey “revealed a wide variety of sizes, shapes, and models of organization,” even as it affirms the value of such coalitions (and statewide champions where coalitions do not exist) in providing support and assistance to individual PPC and hospice programs.

National Coalition for Hospice and Palliative Care, Pediatric Palliative Care Taskforce, Payment & Financing Workgroup

p. 43

Melissa Hunt, PharmD, BCPPS

According to this article, “A convening of national PPC leaders in 2019 identified the need for a pediatric-specific national task force to set field strategy and build field capacity. The intent of the PPC Task Force is to improve national alignment and impact by identifying feasible action items to accelerate advancement of the field and improve children’s access to high-quality palliative care.” By 2021, “The Task Force has identified three key priorities to advancing the field of pediatric palliative care: (1) Payment and Financing; (2) Assessment of Need and Capacity; and (3) Raising of Awareness and Demand.” Further, “The payment and financing workgroup’s overall mission is to ‘Activate interdisciplinary collaborations with key payment & finance decision-makers and create real-world payment & financing solutions to continuously improve access to pediatric palliative care through financial sustainability.’” For more on contacts with the Workgroup, as well as its mission, vision, and goals, read this article.

THE KEY TO BUILDING A SOLID HOUSE STARTS WITH THE FOUNDATION

Tracy Leonard-Warner, MHI, MT-BC

Executive Director

Ryan House

Phoenix, AZ

tleonardwarner@ryanhouse.org

and

Susan Kricun

Director of Marketing and Communications

Ryan House

Phoenix, AZ

skricun@ryanhouse.org

Every day, thousands of children are born with a life-limiting condition or are involved in a life-altering accident that changes the course of their lives dramatically. Doctors' appointments, surgeries, at home care; it can all become overwhelming and exhausting for the child and their family, especially with the current circumstances surrounding the pandemic.

Enter Phoenix-based nonprofit Ryan House. Ryan House provides world-class care and programs and embraces all children and their families as they navigate life-limiting or end-of-life journeys through palliative and respite care that addresses the emotional, spiritual, and social needs of the family. It offers continuity of care from diagnosis to end-of-life.

Founded in 2010, Ryan House is the only facility of its kind in Arizona and only one of three in the country, including George Mark in California and Crescent Cove in Minnesota. Ryan House is more than just a facility – it is an innovative concept in pediatric palliative care. It is a community. It is a home.

The services provided by Ryan House are truly a lifeline for the children and families in Arizona who need them. But the need for these services spans far beyond Arizona. So, what has been the key to Ryan House's success and how can other organizations make their facilities sustainable?

Just like construction on any new home, the key to building a solid house starts with its foundation. Founding partners and community supporters alike are essential, and that starts with funding, explains Ryan House Executive Director Tracy Leonard-Warner.

“One of the keys to Ryan House's success, initially, was the support it received in its first years—way before construction began,” she said. “In 2005, five years before it opened its doors to the public, Ryan House began raising money. In that time, more than 4,000 gifts were given ranging from \$5 to \$250,000 by community supporters and corporations.”

It's been nearly 12 years since Ryan House first opened its brick-and-mortar building and began offering services in Arizona. And, to this day, the key to its success has always been diversity. Ryan House's world

class care is made possible by the support it receives from its community. Currently, there is no reimbursement for facility-based respite care in the state of Arizona. Ryan House's community is what makes this possible. Simply put, Ryan House would not exist without the local support it receives.

Considered a new model of care in the U.S., communities of "like" houses similar to Ryan House exist in two other communities. Each has found what works best for them; the common denominator is broad community support.

"Thousands of people have all made an impact on the children and families we serve," said Leonard-Warner. "In a typical year we have nearly 3,000 gifts ranging from \$5 to \$125,000. A consistent fundraising tactic is the diversity of our donors and supporters.

"Collectively, we made it a point to have broad, diverse community support," she continued. "We don't just rely on in-person fundraisers, especially in light of the current situation with the pandemic. Corporations, individuals, grants, funding campaigns like tax credits, and mail appeals are all things that contribute to Ryan House's bottom line."

To ease the burden of its nearly \$3 million annual operating budget, Ryan House is looking towards reimbursement for respite and palliative care services to help further diversify its revenue, making it even more sustainable. However, Ryan House acknowledges that it will have to continue philanthropy because reimbursement will never fully pay for services the way it wants to offer them.

"It's just one more way we can continue to diversify where our funds come from, but it won't take the place of the fundraising we currently do," Leonard-Warner said.

Additionally, Ryan House finds ways to keep their messages and stories relevant and relatable to others—whether it be stories about genetic defects, near drownings, or the impact of the pandemic, to name a few. The current COVID crisis is a daily reminder of how important it is to be reactive and adapt to circumstances.

"Our goal, no matter what we're doing, is to share our stories of our families," Leonard-Warner said. "During the first year of COVID, we made that pivot and continued sharing our families' stories that were relatable to what people's needs were in that moment."

Ryan House has remained open to keep the children it serves safe and out of the hospital. It pivoted its care to ensure it can provide families with what they need as they continue to navigate the current crisis. Families are dealing with increased stress of keeping their immuno-compromised children safe during a pandemic, lack of school for their medically fragile children and their siblings, financial hardship related to job loss or furloughs, costly medical care, and caregiver burnout due to the 24-hour-per-day demands of caring for a terminally ill child.

These are just a few examples of what Ryan House has been sharing to keep its stories relevant with the community, in hopes that it will continue to receive the mission-critical funding needed to continue to improve the lives of children with life-limiting conditions and their families.

With the daily cost of caring for each child just over \$1,000, each gift Ryan House receives supports the care and the environment in which it is provided. So, it only makes sense that in addition to having a

diverse community of support, Ryan House must also understand and incorporate clear and consistent messaging through marketing and PR efforts.

Ryan House's community also gives back in sweat equity on a consistent basis through volunteering, whether virtually, at the house, at events, or on a per project basis. Plus, Ryan's House understands that the families it serves are a tremendous resource – not necessarily for funding, but for stories and for new contacts that have a tie to its mission. Relationships and volunteer recruitment are also key to its diversity.

“We do our best to always lead with the good stuff when it comes to storytelling for Ryan House,” Leonard-Warner said. “And, at the end of the day, it's really all about relationships – long standing relationships, as well as making new ones along the way.

“Our care team experiences joy and sadness daily. There might be a dance party going on and at the same time, a patient not doing well just down the hall. For us, creating moments for families is where it's at. It's very rewarding and it's what keeps us going,” Leonard-Warner said.

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IS A COMMUNITY- BASED PEDIATRIC HOSPICE PROGRAM SUSTAINABLE?

Holly Davis, MS, APRN

AVP of Clinical Services

Hospice & Palliative Care Charlotte Region

Charlotte, NC

Co-Chair, National Hospice & Palliative Care Organization (NHPCO) Pediatric Advisory Council

National Pediatric Palliative Care Task Force member

National Coalition for Hospice & Palliative Care

DavisH@hpccr.org

That is a question often asked by Executive Directors, CEOs, hospice leaders, and pediatric professionals alike. And the answer is yes! It can be. But there is no cookie cutter for a community-based pediatric hospice program. There are many models of care for pediatric hospice services. Reimbursement for pediatric hospice services can be challenging. So, where do you start? How can you make it work?

In this article, I hope to share with you three pillars to help you build a sustainable community-based pediatric hospice program. Through years of trial and error, program development, and conversations with key stakeholders, I have learned some basic “must dos,” that I refer to as pillars, to help get a community-based pediatric hospice program off to a good start.

Many community-based hospice providers across the country know that offering pediatric hospice services is the right thing to do. Many hospice organizations start serving pediatric patients because of that notion. However, to build a pediatric hospice program that is sustainable, a strong foundation must be built.

Community-based pediatric hospice programs funded solely on philanthropic support are difficult to sustain over the long haul. Can it be done? Yes, but establishing a financially sustainable infrastructure takes the burden off fundraising for much needed pediatric hospice services. In today’s hospice landscape, where organizations’ funds are tight due to the COVID pandemic, rates cuts, increased regulatory oversight, and quality outcome measures, building a financially sustainable community-based pediatric hospice program is a must if an organization’s leadership is even going to consider adding and/or maintaining the service line.

So, what should you do if you want to start a pediatric hospice program? Well, the path will be bumpy, and you will learn a lot along the way, but there are some “must dos” in building the foundation.

The three pillars for building a sustainable pediatric hospice program are:

1. Concurrent Care for Children
2. State Coalitions
3. Organizational Assessment

Let’s start with the first pillar: **Concurrent Care for Children**. In 2010, the Affordable Care Act (ACA), Section 2302, federally mandated hospice services for children, from birth to their 21st birthday, through Medicaid and/or Children’s Health Insurance Program (CHIP). Written within these two short paragraphs, Concurrent Care for Children allowed for curative/life-prolonging treatments and services to

be offered alongside hospice and palliative care services, and for those services to be billed for and paid separately. What does all that mean? Well, basically, it means that the child who is hospice eligible (has a prognosis of 6 months or less life expectancy in most states) does not forgo any curative or life-prolonging treatments or services when hospice is elected. Electing hospice services does not waive the child's right to receive any curative and/or life-prolonging services. The provision goes further by stating that curative and/or life-prolonging services can be billed for and paid separate from the hospice reimbursement. This means that the hospice is not responsible for curative and/or life-prolonging services. All those services would be billed and paid for outside of the hospice benefit.

Concurrent Care for Children changed the pediatric hospice landscape. When a child is admitted to a hospice program, that hospice program determines what will be covered under the hospice benefit, such as Durable Medical Equipment (DME), medications, treatments, therapies, etc. Prior to 2010, if the hospice program determined that an item/medication/treatment would not be covered under the hospice benefit, the child/family would have to either pay for the item/medication/treatment out of pocket or forgo it. Under Concurrent Care for Children, those curative and/or life-prolonging items/medications/treatments determined to be not covered by the hospice benefit can be billed and paid for under the state Medicaid or CHIP plan.

Since 2010, hospice programs have had the opportunity to work with their state Medicaid offices to implement the Concurrent Care for Children provision. This leads me to the second pillar, **State Coalitions**. It is key for hospice providers to work with your state coalition and/or other pediatric hospice providers within your state. Consistent determination of hospice coverage of DME, medications, treatment, and services is key for billing and payment. If all the pediatric hospice providers are consistent and on the same page with determining what is curative and/or life-prolonging and what is hospice, palliative, and/or comfort care, then presenting that to the state Medicaid office in a clear, consistent message is beneficial in the implementation of Concurrent Care for Children. If your state does not have a state coalition, then reach out to the hospice providers in your state. Find out which organizations provide pediatric hospice services. Schedule a call or a meeting with all the pediatric hospice providers. Discuss what is working well, where are the sticking areas, what have you found to be helpful. Talk through scenarios, such as hospitalizations, private duty services, respite, etc. This collaboration is not about how many children each hospice has on services, referrals sources, or contracts, but about the big picture of establishing the framework for Concurrent Care for Children.

Here is an example where this type of collaboration can be helpful. Recently, during a meeting with pediatric hospice providers from the same state, a provider mentioned that they had run into issues with getting non-hospice covered medication processed thru a community pharmacy. This hospice, we will call Hospice A, shared that the community pharmacy was unable to process the medication without billing it to the hospice despite the medication being a curative therapy. Another hospice provider, Hospice B, spoke up and shared that the Medicaid system had recently updated and that an additional "step" was added in order for the community pharmacy to overhead the "hospice edit" in the Medicaid system. Knowing that piece of information had a huge impact of the Hospice A's financial sustainability. In an effort to prevent the family from waiting at the pharmacy or becoming frustrated, Hospice A had been covering the medication costs, which was negatively impacting the financial sustainability of the program. Whereas Hospice B, utilizing Concurrent Care for Children, was able to appropriately bill for hospice covered and non-covered medications. Thus, maintaining a more financially stable bottom line.

Once you understand Concurrent Care for Children and you are working within your state coalition, the third pillar focuses on an **organizational assessment** of your organization. Community-based pediatric

hospice program models vary from one organization to another. Some organizations have dedicated pediatric hospice staff while other have an integrated hospice model, where staff care for both pediatric and adult patients; and others have hybrid models. There is not a right or wrong way. For sustainability purposes, an organization may start out with an integrated or hybrid model with the goal of moving towards a fully dedicated pediatric hospice team.

Start with an organizational review. Who among your staff have pediatric experience? Who is interested in pediatrics? What areas, departments, or teams have the ability to support pediatric patients? Where does pediatric expertise need to be built up or added? For example, is the admissions department able to admit a pediatric patient? Is After Hours able to support pediatric patients? Is the finance department able to manage and bill Concurrent Care for Children properly? What systems and/or processes within your organization make sense for pediatric patients and what needs revision? It is important to integrate quality and regulatory checks and balances for the pediatric program within the organization's structure. For example, if one department or staff member reviews all the admission documentation for accuracy, then having that same department or staff member review the pediatric admissions for accuracy would be helpful. Integrate what makes sense and dedicate staff for those tasks that require pediatric expertise.

Building the infrastructure for a pediatric hospice program lays a solid foundation for long term sustainability. Philanthropic support to start a pediatric hospice program is extremely helpful; however, having a sustainable pediatric program long term requires financial infrastructure.

After a pediatric hospice program has laid the foundation, growth can go in various ways based on the organization's mission, vision, and the community it serves. For example, maybe a pediatric hospice program wants to expand and implement a perinatal palliative program. These pillars are basic building blocks to a sustainable community-based pediatric hospice program. Checking these items off your list will get you moving in the right direction for long-term success.

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HOW TO SUSTAIN A PEDIATRIC PALLIATIVE CARE PROGRAM IN THE COMMUNITY

Kristen Eisenman, MD

Pediatric Palliative Care and Hospice Physician
Footprints Children's Services
The Denver Hospice
Denver, CO
keisenman@care4denver.org

Kimberly Statler Bennett, MD, MPH

Pediatric and Adult Hospice and Palliative Physician
Footprints Children's Services
The Denver Hospice
Denver, CO
kbennett@care4denver.org

and

Susan Finke, RN, CHPN

Director of Clinical Services
The Denver Hospice
Denver, CO
sfinke@care4denver.org

The Denver Hospice was founded in 1978 in Denver, Colorado, to provide hospice and palliative care to our community for people of all ages. Our values, beliefs, and not-for-profit status are key to our ability to provide consistent high quality, compassionate care and fulfill our mission of encircling those facing advanced illness with unprecedented levels of comfort, compassion, and expertise. We support our belief that no matter where you are in life's journey, you deserve to get the most out of every day, should have more opportunities to create memories and moments of joy, and have less pain and more quality of life.

Footprints Children's Services is a community-based program of The Denver Hospice which has provided seamless care from diagnosis through treatment, from palliative care through hospice care, and from anticipatory grief counseling through bereavement for over 40 years. Pediatric patients and their families are particularly vulnerable, have specialized needs, and require specialized care. Footprints Children's Services offers three pediatric-focused programs to support children and families at varying stages along the continuum of the disease process: Pediatric Palliative Care at Home, Children with Life Limiting Illness (CLLI) waiver services, and pediatric hospice care.

Our program, like so many others nationally, has encountered many challenges to financial sustainability for community-based pediatric hospice and palliative care. Pediatric hospice and palliative care are clinician intensive (MD, NP, RN) programs with reimbursement guided primarily by contracting with commercial insurance companies. To ease contracting and billing, establishing a physician group National Provider Identifier (NPI) and becoming an in-network provider was beneficial. Reimbursement

and participation requirements in a state Medicaid pediatric hospice waiver program will vary state to state. Examination and understanding of the state waiver and reimbursement structure was important in guiding program design from what disciplines to hire, job description requirements, and what services to provide.

In Colorado, the pediatric hospice waiver program provides reimbursement for various disciplines under the CLLI waiver. CLLI is a Colorado Medicaid waiver program eligible to children younger than 19 years of age diagnosed with a life-limiting illness, defined as anticipated death due to their disease before reaching adulthood. In addition to the provider services offered via the Pediatric Palliative Care at Home program, patients enrolled in CLLI waiver services through Footprints Children's Services program become eligible to receive more robust psychosocial and symptom management support, including skilled respite services, massage, music, art therapy, and individual and/or family counseling. This support is provided from our social workers, chaplains, child life services, bereavement services, and Registered Nurse.

Beyond financial challenges, dedicating resources to pediatric care is imperative. Consideration must be given to staffing, contracting, credentialing, after-hours coverage, and hospice in-patient levels of care. Hiring and/or contracting for staff with specific pediatric training at end of life can be challenging but it is also vital to ensure clinical expertise is available 24/7. Hospice in-patient levels of care (general inpatient and respite) present unique challenges, as many hospice inpatient settings are designed for adults. Creating a room kit to convert adult rooms to age-specific pediatric settings has been well received. We developed pediatric basic hospice orders and a 'pediatric hospice tape' that allows a person at bedside to have visual reference to refer to when talking to our call center staff or providers.

As a mission-based not-for-profit, The Denver Hospice believes supporting our pediatric population despite financial challenges is not only needed in the community but is the right thing to do. Our philanthropic support reaches out to the community, sharing patient stories that demonstrate how donations have provided for the needs of our pediatric population and their families. This feedback to the community illustrates how we can give hope and offer opportunities for play to the children and families in our care. We also have restricted funds created specifically to address the non-medical needs of families, providing family assistance grants for needs such as food, rent, utilities, travel expenses, summer camps, and other activities. Families experiencing end-of-life issues often have disruptions to income and run into financial difficulty. Fundraising opportunities such as direct mail appeal and various events enrich the program and services provided.

In the 40 years since the hospice benefit was added to Medicare and Medicaid, the industry has matured. Organizations have strong metrics guiding financial best practices. Palliative programs are necessary to ensure individuals receive care to relieve pain and suffering associated with a serious illness, but they are poorly funded. By following the outlines of the adult hospice model, pediatric hospice is sustainable. Careful consideration and structure are needed to sustain palliative care for adult and pediatric patients. Structuring the pediatric program as a division of a full-service adult hospice creates synergies which can lead to sustainability.

One of the biggest challenges to advancing care for children with complex, chronic illnesses is the ability to offer a full range of comprehensive services: palliative care, CLLI waiver, anticipatory grief counseling, hospice, and bereavement support. Offering these clinical and therapeutic services "under one roof" is appealing to families as it eases their burden from having to find these supports "a la carte" from various providers. To guide sustainability, our program continually reviews and refines current state to

learn what we can do to improve future state. Our commitment remains steadfast to meet the needs of our community by providing accessible and excellent care that spans the continuum of disease encountered by children and families facing serious and life-changing childhood illnesses.

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PANDAS: HOW TO AVOID THE ENDANGERED SPECIES LIST, OR, SUSTAINABILITY OF AN INPATIENT PEDIATRIC PALLIATIVE CARE TEAM

Deborah Fisher, PhD, RN, PPCNP-BC, CHPPN

PANDA Palliative Care Nurse Practitioner

Children's National Hospital

Washington, DC

Dfisher@childrensnational.org

Almost 70% of pediatric hospitals have inpatient pediatric palliative care teams (Rogers et al., 2021). Although there is a growing body of evidence of the growth of pediatric palliative care, there is little known about what leads to the demise of a program. In this article we will discuss the rise of a little program that had a robust start yet was unable to sustain itself. Fortuitous circumstances led to the reestablishment of the team which has since continued to survive through several layers of support. It is through this example that we will explore how to avoid the endangered species list.

For the past 10 years, the Pediatric Advanced Needs Assessment team (PANDA) has grown and thrived despite an earlier failed attempt to populate the habitat of a National Children's Hospital in 2005. For the sake of this article, pediatric palliative care teams will be referred to as PANDAs. Those PANDAs were unable to sustain themselves with the level of support offered which led to the unfortunate extinction of the program. Later, a miracle occurred, and the PANDAs returned! So, what are these previously extinct bears doing differently now?

With all teams (PPC), or PANDAs, money is important to keep the roof over your head and for the care and watering of your PANDAs. Financing is partially through billables and is often subsidized through hospital funding and in some lucky programs, philanthropy offsets the hospital's investment. So, what is a sustainable financial model? Most successful programs are financed through three entities: (1) insurance billing; (2) philanthropy; and (3) organizational support.

Insurance: As with other palliative care programs, billing for time is recommended to best capture the benefits of time with PANDAs.

Philanthropy: Similar to Scarlett O'Hara, PANDAs rely on the kindness of (generous) strangers who soon become PANDA Friends & Heroes. Although this current habitat has not yet received funds for endowed positions, it is the ultimate goal to create self-sustaining funds for individual PANDAs. Nonetheless, some PANDA specialists such as massage therapists and acupuncturists have been funded by philanthropy. Search online and partner with your hospital charitable foundation to keep an eye out for grant opportunities. Insider tip: not everyone understands what it is that PANDAs do (Meier et al., 2017). It is wise to meet with your local foundation to teach them all about the nature of PANDAs and the special ways their own local species of PANDAs can help support the patients and families in your habitat. Once understood, everyone loves PANDAs!

Organizational Support: Make the argument for why the hospital needs PANDA. How does PANDA support hospital priorities? Whether the strategic agenda is world domination, cost avoidance, or simply doing the best with the resources at hand, you must align yourself with these organizational goals (Gans et al., 2012; Gans et al., 2016). What are the consequences of not having a program? What if the

PANDA became extinct? Many people would be sad, especially the little humans and their families. To answer this important question, you will need to do an ecosystem check.

Ecosystem check: What other programs depend on PANDAs? Per *U.S. News and World Report's* ranking system, oncology needs PANDAs to care for children at least 30 days before death. Do PANDAs benefit other programs? In one village, bone marrow transplant, families endorsed their desire to have PANDA support, which led to their interest in choosing CNH BMT program. Apparently, not all BMT programs have PANDAs as part of their standard of care (Gans et al., 2012; Lafond, Kelly, Hinds, Sill, & Michael, 2015). All 10 programs ranked in the top echelon by the *US News & World Report* have strong palliative care programs. Someone's got to be number one, why not you?

Who can guide us in firming up a strong habitat? Use the Center to Advance Palliative Care (CAPC) program development and sustainability information. These conservation experts are specialists in creating and sustaining dens and habitats for PANDAs.

As much as pediatric palliative care providers want to say yes to everyone who wants or needs PANDAs, to sustain this practice, staffing needs to be in place. In fact, there is a positive correlation between number of funded staff in a PANDA program and numbers of new patients seen (Feudtner et al., 2013). More PANDAs equals more little humans seen and supported to live their best lives!

How do we talk to skeptics or nonbelievers in PANDA?

Metrics and Benchmarking: Keep valuable metrics. Join and participate in the Pediatric Palliative Improvement Network for access to benchmarking metrics and national pediatric palliative quality improvement projects. Groups like this help to capture lots of "proof" of why everyone needs PANDAs. Again, refer to organizational strategic goals and align your PANDAs with the habitat's goals. If pediatric palliative care behaves similarly to adult palliative care, the hospital will realize significant cost savings as intensive care use by little humans decreases. Decreased intensive care stays opens beds in beleaguered intensive care units. Keep in mind that PANDAs provide quality care for people of all ages—including the little humans.

Join the Palliative Care Quality Collaborative—you may recall the CAPC National Registry. This repository of program data and metrics is now housed in this unique cooperative partnership. You may wonder if this group is PANDA friendly. There is now a special den for PANDAs! Here you can compare your PANDA den to other PANDA dens (Rogers et al., 2021).

As mentioned earlier, PANDAs live in their natural habitat (inside hospitals) and are not usually seen in remote nature reserves (rural areas or outside hospitals). No matter where your PANDA dens are located, care for these rare wildlife species must be maintained for your PANDAs to thrive.

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SUSTAINING A THRIVING PEDIATRIC PALLIATIVE CARE PROGRAM: FOOTPRINTSSM

Aimee Roddy, RN, MSN, CPNP-PC
Palliative Nurse Practitioner
SSM Cardinal Glennon Children's Hospital
St. Louis, MO
aimee.roddey@ssmhealth.com

and

Katheryne Amba, PhD, DNP, CCRN, ACNP-BC
Nurse Scientist
SSM Cardinal Glennon Children's Hospital
St Louis, MO
katheryne.amba@ssmhealth.com

Pediatric palliative care aims to alleviate suffering and improve the quality of life of children with serious disease and increase support for their parents and other family members (Snaman et al., 2020). FootprintsSM is a palliative care program unique to SSM Cardinal Glennon Children's Hospital (CGCH). CGCH is a not-for-profit 195-bed inpatient and outpatient children's hospital located in St. Louis, MO. Patients include children of all ages from St. Louis, its surrounding area, and across the country. It is a Level 1 Trauma pediatric hospital with a Level 4 Neonatal Intensive Care Unit (NICU) and is Magnet[®] accredited with more than 200 specialists in multiple medical and surgical subspecialties. CGCH has achieved Magnet[®] recognition, which is the highest national honor in nursing excellence. In this article, we describe a thriving pediatric palliative care program, its history, and the factors that have enabled the program to be sustainable. Some factors that have promoted sustainability with the CGCH palliative care program include but are not limited to patient-centered care, a reliable fiscal support, consistent and skilled workforce, true collaboration, and communication amongst the health care team members.

The FootprintsSM palliative care program at CGCH was started in 1998 by a group of dedicated caregivers. It was supported initially by a grant from the Robert Wood Johnson Foundation, to meet hospice and palliative care needs of pediatric patients and families. While palliative care has emerged partly as a response to acknowledgment of unmet needs among patients nearing the end of life, some of the needs are distinctive in their breadth, often requiring expertise from diverse fields (Yedidia, 2007). Like most palliative care programs, the focus of the palliative care service at CGCH is to address the needs and concerns of children with complex illnesses. The FootprintsSM palliative care program uses a hospital-based approach dedicated to care coordination between families and their medical providers, as well as advance care planning (Linebarger & Moreno, 2019). According to the FootprintsSM palliative care program administrative assistant, total caseload records of patients consulted in 2021 was 298, a marked increase from 230 patients in 2020. There is a progressive increase in palliative patient caseloads consistent with national levels (National Palliative and Hospice Care Organization, 2020).

The FootprintsSM palliative care program is comprised of an interdisciplinary team in line with Institute of Medicine (IOM) standards of palliative specialty (IOM, 2003; IOM, 2015). The FootprintsSM staff members are comprised of two attending physicians, two advanced practice nurses, two registered nurses, a

social worker, and an administrative assistant who are committed to supporting the patient's journey. The program does not have a dedicated chaplain, but being a faith-based institution, chaplains are available at any time and are readily involved with palliative care patients as needed. Other important teams the program collaborates with include child life experts, psychologists, music, dance, and art therapists. The care team is multidisciplinary and very devoted to improving the quality of life of the patients.

The palliative team engages with patients on an ongoing basis to identify challenging issues which arise during illness/hospitalization. Team members work diligently with a plan of care where special attention is given to the patients' values and beliefs, striving to provide comfort, advocacy, and support that addresses the family needs to cope and thrive. Although the core principles of palliative care are well established, such as pain and symptom management, supporting caregivers and family members with respect for the patients' goals of care is vital (Cassel et al., 2018). The FootprintsSM program operationalizes palliative care principles with a unique touch that sets it apart from other programs. Meeting children and their families at a time of complex illness diagnosis or new life-changing events has created opportunities for the FootprintsSM multidisciplinary team to have a deeper and more fulfilling trust-based relationship with patients and families. Spending time and providing undivided attention to palliative patients and family members has helped the FootprintsSM team members to gain an appreciation of key health moments and family dynamics amongst patients. A better understanding of patients and families has contributed to incorporating a multidisciplinary and integrated approach in care that is patient centered.

Patient-Centered Approach Care

One of the factors that keeps the palliative care program sustainable at CGCH is the application of a patient-centered approach philosophy when interacting with the patients and family members. At CGCH, when a child is diagnosed with a serious illness, families are empowered to step back and look at a new normal for what the child's life will be. Families and patients are encouraged to explore the bigger picture to help the medical team best align with their ideals for their child's quality of life. Parents are allowed time to discuss and express their understanding of a diagnosis, and the implications of the complex health situation. A patient-centered approach of care is taken into consideration when interacting with patients and families (Yedidia, 2007). It is important to emphasize that these activities require time, care, and concern. The palliative care team collaborates with other care providers, collects information from the various care partners, and presents the information to the family who is encouraged to be in control of their health care. During the collaborating phase with the patients, a care conference is organized, and a social worker and chaplain are readily available to provide emotional and spiritual support.

Consistent and Skilled Workforce

The FootprintsSM palliative care program has high quality caliber of multidisciplinary staff members with each having at least ten years of health care experience. Despite the high demands of the job and high caseloads, the members demonstrate a commitment to palliative care as exemplified in their work ethics. The program's attrition or turnover rate of staff is zero percent. The low turnover may be attributed to many factors, but the staff members pride themselves on true collaboration amongst the team that creates a healthy work environment and fosters cohesiveness. According to the American Association of Critical Care Nurses (2005), healthy work environments have the propensity to promote staff satisfaction and increase job retention.

Reliable Fiscal Support and Sustainability

The FootprintsSM program, just like most palliative care programs, is not an income generator for the institution. The program was funded initially through a Robert Wood Johnson Foundation grant at its inception. Upon completion of the grant, CGCH and the Glennon Foundation became responsible of the program's running costs. One of the recommendations with "Dying in America" (Institute of Medicine, 2015) was for public and private payers as well as care delivery organizations to cover the provision of comprehensive care that is accessible and available to individuals on a 24-hour schedule. Fee-for-service charges are generated through the medical providers (physicians and nurse practitioners). The providers bill for palliative services as they consult with patients. Nevertheless, the reimbursement rate is not enough to support the program financially.

The Glennon Foundation is the biggest source of financial support for the FootprintsSM program. The foundation conducts fundraising activities on behalf of the program. To be accountable and sustainable, the medical directors apprise the Glennon Foundation board of directors periodically with their activities and impact. Through the appraisals, the medical directors play a vital role in justifying the expenditures and needs for the program. The accountability meetings allow the board members of the foundation to appreciate and understand the impact of the FootprintsSM program, thereby ensuring steady fiscal support and sustainability. Additional sources of fiscal assistance are received from philanthropic donations from family trust funds and community members.

True Collaboration and Communication

True collaboration and communication have been vital factors that assist with the sustainability of the palliative care program at CGCH. According to Hendricks-Ferguson et al. (2017), collaboration of physicians and nurses during palliative care discussions has been associated with improved parent satisfaction with provider communication. The palliative care team after meeting with the patient and family members plays a significant role in providing an additional layer of support to patients, family caregivers, and the primary medical team through close attention to symptoms, emotional needs, and spiritual needs (Epstein, Goldberg, & Meier, 2012). The FootprintsSM physicians and advanced practice nurses collaborate with other clinicians in discussing the family's goals of care. The advanced practice nurses join forces with patients and families at times of difficult decision making and assist the primary medical teams in creating recommendations for improved symptom management. The social worker at the FootprintsSM program has a unique role since the role is operated primarily as parent and family support. The social worker assists families with exploring anticipatory grief, learning coping strategies in the context of a complex medical diagnosis, and normalization of the stress responses of the child and parent. Additionally, the social worker facilitates bereavement through counseling, both with anticipatory grief and ongoing grief support for 48 months post death of a patient. Gradually, pediatric palliative care services are changing families' perceptions of palliative care, as well as understanding the importance of addressing their child's needs, families' values, and ideas about quality of life. Attending to a child and family's overarching goals of care has a profound effect on how the child manages the illness and learns to cope with the ailment.

Education and Misconceptions on Palliative Service

To keep the FootprintsSM palliative service program sustainable, members of the palliative care team are engaged in educating not only the patients and family members but also the hospital staff in general on

basic principles of palliative medicine. Education is vital because lack of education can present or promote misconceptions about palliative care which may pose challenges on patients receiving care. Inadequate education about the numerous services provided by palliative care consultants can lead to reluctance by primary health care providers in placing consults. Studies have reported limited awareness and misconceptions about palliative care (Shalev et al.,2018).

It is not uncommon to find clinicians, patients, family members, and the public associating palliative care with end-of-life care or hospice. A negative result of the limited awareness and misconceptions about palliative care services can lead to late referrals, thereby delaying care (Dionne-Odom, Ornstein, & Kent 2019; Flieger, Chui, & Koch-Weser, 2020). Additionally, there is concern for a lack of pediatric-trained palliative and hospice providers in outlying communities. Currently CGCH does not have a pediatric outpatient home care service. Home nursing for our palliative and hospice needs is done through the Barnes Jewish Care Wings Program (a home-based pediatric hospice and palliative care program of Barnes Jewish Health Care) for patients and families living within the local St. Louis area. If the patient lives outside of the range of services for Barnes Jewish Care Wings Program, alternate services will be required which may lead to discontinuity of care since some providers may not be able to care for pediatric patients. This further highlights the need to educate providers about pediatric palliative and hospice care, necessitating the need for palliative care programs in rural areas.

Clinicians need to be educated on the benefits of palliative care as well as the distinctions from hospice care, and when to properly consult for palliative care services. Members of the FootprintsSM program at CGCH continuously educate not only the bedside clinicians but also patients and family members on the benefits of palliative care with complex illnesses. Other efforts by the palliative care team to increase sustainability via education include bedside clinical rounding with patients, educational seminars on palliative care, participating in professional conferences, evidence-based practice activities, and research. The FootprintsSM program staff members are planning on embarking on more rigorous education formats such as monthly journal clubs where knowledge can be exchanged. These educational activities promote collegiality amongst staff members, increase productivity, create a positive presence amongst interdisciplinary staff, and assist with sustainability of the program.

The FootprintsSM palliative program at CGCH, like most programs, has its challenges but the dedicated staff as well as the patients and family members play a major role for its sustainability. Future sources of revenue for the program could be explored through grants or research. In previous years, philanthropic donations from family trust funds and donors have provided fiscal support to sustain the program. Nonetheless, philanthropic support and goodwill gestures are not a constant source of revenue to sustain the program financially. Recruitment of additional staff, especially a board-certified pediatric palliative physician, may boost productivity and spur research into better methods of self-sustaining a palliative care program. The FootprintsSM program currently has a budget for a board-certified palliative physician but recruiting the right candidates is a process still in the pipelines and yet to materialize. In this article, we have discussed a unique pediatric palliative care program in a hospital and the factors that have permitted the program to self-sustain, as well as some challenges faced by the program with future recommendations for best practice.

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KEYS AND IMPORTANCE OF SUSTAINABLE PEDIATRIC PROGRAM DEVELOPMENT: LESSONS FROM NEVADA

Angela Berg, DNP, APRN, CPNP

CareOusel Pediatric Program at ProCare Hospice of Nevada

Las Vegas, NV

kidzrn29@gmail.com

Overview:

Palliative care is a specialized medical care for those suffering from serious illnesses and is gaining more recognition around the world in recent years. Data from 2000-2016 show that the U.S. is up to 75% of hospitals with greater than 50 beds having developed a palliative care program for adults (Center to Advance Palliative Care, 2018). This same report cites the availability of such services being extremely variable and urges the importance of more community program development to improve access to palliative care across the country.

This specialized care for children, pediatric palliative care, is struggling to grow at the same rate as these adult programs—with most growth being in the children’s hospital setting (Rogers et al., 2021). In 2010 the Patient Protection and Affordable Care Act (ACA) recognized the need for children with medical fragility to receive palliative care through the hospice benefit while concurrently receiving treatment for any of the conditions they suffer (Ibid.). This became known as the concurrent model of hospice care.

In this article, we share our experiences in Nevada in developing and growing a home-based program for children using the concurrent care model and the lessons learned about sustainability.

Model: Concurrent Care

Palliative care is focused primarily on improving quality of life, experiences of patient and family, and use of health care resources (Cassel et al., 2018). This translates to palliative care across the entire life span, including pediatrics.

Review of several years of birth, death, and Medicaid data for Nevada in 2014 showed that there are approximately 300 children living at any given time in the state with conditions that could benefit from pediatric palliative care under the concurrent care model. Traditional hospice services are resisted by parents and health care providers alike for children due to the limitation of providing any ongoing therapies that might prolong the life of the child. When the ACA removed this limitation in 2010, understanding among health care providers was poor and the concurrent care model has been poorly adopted with 40% of hospice organizations refusing to enroll patients under concurrent care (Rogers et al., 2021). Some states have not adopted the concurrent model of pediatric hospice services at all. Fortunately for many, Nevada did adopt the concurrent care model for children, thus opening the path to providing this valuable service for those parents struggling to navigate a complex medical system while being able to give their child every possible chance for a trial of life.

Understanding concurrent care is a challenge for most anyone not working in this industry for several years, yet alone parents and entry level staff working in payer positions. Partnering with Medicaid to develop that understanding together was critical, took several years, and continues to be a challenge. Clear and consistent communication is key in making sure cost-effective care with best possible outcomes can continue. Working with state level government agencies and taking part in advisory committees, when possible, will prove to be well worth the investment of time. COVID has brought about a setback because many meetings not considered “essential” have been postponed. It will be our obligation as health care advocates to encourage activity of these committees to be resumed as the pandemic continues to linger.

Staffing models for concurrent care supply opportunities for traditional hospice agencies to consider the acuity differences if they choose to take part in this type of care model. Development of metrics in pediatric palliative care has seen little activity in comparison to adult hospice and palliative care (Thienprayoon et al., 2021). There are many opportunities to develop standard measures and practices. In addition, The National Palliative Care Registry is actively trying to gather and share data from across the country. Participation with the Registry is critical so that standards are developed with consistency and proper input. Data collection is imperative to showing the need for pediatric palliative care in any community (Doherty & Thabet, 2018).

Key: Relationships

One of the most essential factors in developing a concurrent care program in a sustainable model is developing relationships in the community. Partner relationships include payers (with significant focus on Medicaid), hospital partners, therapy providers, and other programs serving similar patient populations. Maximizing success from these relationships will be most promising if formal and informal aspects are considered. Within your discipline you can often find the most supportive of these relationships. The Palliative Care Leadership Centers developed by Center to Advance Palliative Care (CAPC) are one possibility that is readily available (Cassel et al., 2018). Networking opportunities are afforded regularly through membership in CAPC and the National Hospice and Palliative Care Organization (NHPCO). These have been extremely helpful for developing informal collegial relationships.

Being a good partner to your fellow health care professionals in the community will be the best tool you will ever have. Concurrent care provides a safety net for medically fragile children that few can imagine. Parents can have a fully supported medical home environment in their home, while still functioning as parents instead of insurance and health care navigators. Being the highest quality coordinator and communicator to the multitude of members of the complex child’s health care team is of the utmost importance in being able to achieve the goals of care. The advantage of a hospice concurrent care model is that all disciplines work together in full collaboration to ensure that the child and family outcomes always remain central. It would be exceedingly difficult to duplicate this in an office visit model of care.

Key: Education

Raising awareness and educating yourself, your team and organization, and the payer community becomes important for all key stakeholders to buy in to the development of the program. Doherty and Thabet (2018) wrote about starting a pediatric palliative program in a developing country and identified the following key elements for success: (1) raising awareness and sensitizing hospital administrators and clinical staff about pediatric palliative care; (2) providing education and training on pediatric palliative

care for clinical staff; (3) forming a pediatric palliative care team; and (4) collecting data to characterize the need for pediatric palliative care. This information applied to the lessons we learned in Nevada while starting a program and would likely translate to anywhere in the world.

Becoming the subject matter expert in this type of care comes only with experience. As you gain experience, consider your options for being able to provide education that offers continuing education credits to those you are trying to reach. This allows you to set yourself in front of those needing to see you as the subject matter expert and open networking opportunities to grow your program. Consider train-the-trainer programs and curriculums as an effective way to expand your educator opportunities without reinventing education from scratch. An added benefit is that the partnerships you develop while being part of an educator network will enrich you personally and professionally.

Key: Continuous Quality Improvement

Once a program begins, it is imperative that leadership and the clinical team make continuous quality improvement a priority. Meeting at regular intervals to look at processes and how the program is meeting the desired measures allows for opportunities for early intervention to stay ahead of undesired or unintended complications or risks.

CMS does not have well-defined differences and guidelines for concurrent care under hospice, so it is necessary to use your colleagues and gain from their experiences as you navigate meeting conditions of participation for hospice and develop concurrent care simultaneously. Participating in health care learning collaboratives are an effective way to build your QI strategy and has been successful for The Pediatric Palliative Improvement Network (Thienprayoon et al., 2021).

Risks to sustainability

As with all innovative programs, there are risks to supporting your sustainability. Examples include financial risk and insufficient reimbursement, along with provider/staff burnout and inability to meet the clinical demand (Rogers et al., 2021). Becoming complacent is a mistake easy to make once you realize some success. Keeping a chart or notes of your successes and lessons will serve you well. Remember to review your notes regularly and celebrate both your successes and your opportunities to improve!

Happy 2022 to everyone and wishes for much success in providing this incredible service to the children and their families that receive such great help from it.

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SUSTAINABILITY OF PROGRAMS FOR CHILDREN AND FAMILIES IN MICHIGAN

Elizabeth Rocha, RN, BSN, CHPPN
Associate Vice President, Chief Clinical Officer
Hospice of Michigan
Ann Arbor, MI
erocha@hom.org

There can be nothing more devastating to a parent than hearing that their child faces a potentially life-limiting illness, no matter what the age or health condition of the child. Their world seems to stop, and they don't know where to turn. This article provides insight into our pediatric hospice's model to stretch and tailor our services from the tiniest of prenatal hospice babies to adolescents and young adults who present with a wide range of medical conditions across a whole host of stages.

Model for Successful Transitions

Families with seriously-ill children in Michigan are fortunate to have a set of specialized resources available offering a variety of programs designed to facilitate a smooth transition from curative care to hospice care across a wide range of ages and conditions. The Jo Elyn Nyman Anchors Programs for Children exists as the umbrella program to help children and their families navigate the rough waters of life-limiting illness, eliminating gaps in service and providing care team continuity. The three unique programs offered through the Jo Elyn Nyman Anchors Programs for Children—Compass Support Services, the Anchors Perinatal Program, and the James B. Fahner MD Pediatric Hospice Program—each serve a distinct need for the most vulnerable patients and their families facing a journey no one wants to take. The creation of these three programs allows us to cover the diverse pediatric population we care for and service our state in a way that just one pediatric hospice program may not be able to.

With a focus on maximizing the quality of life for every child, we are privileged to offer a wide range of pediatric services to families through the Jo Elyn Nyman Anchors Programs for Children, which includes a perinatal, a pre-hospice, and a formal hospice program for terminally-ill pediatric patients and their families.

- *Anchors Perinatal Program* provides emotional, social and clinical support to expectant parents as they anticipate and prepare for the birth of their child while also grieving the anticipated loss of the child during pregnancy, birth, or shortly after. The program also assists parents with birth planning during this most difficult time.
- *Compass Support Services* provides experienced pediatric social workers to provide emotional, social, and decision-making support for the child, parents, and siblings, connecting them with specialized community resources to assist with financial, emotional, social, legal, and other needs. Compass is a way for families of children with complex, chronic illnesses to access community programs to make their lives less stressful.

- *James B. Fahner MD Pediatric Hospice Program* provides an experienced team of pediatric-trained staff to care for terminally-ill children and their families. The program offers comfort care, nursing, spiritual care, emotional support, and grief support.

None of this Happens Without Funding/Financial Support

While it goes without saying, none of this would be possible without funds to run these programs. Hospice of Michigan has been fortunate to receive significant funding for these programs from many generous benefactors who believe in our mission of maximizing the life of every one of these children under our care. While some hospice programs struggle to even establish one pediatric hospice program, many of them part-time, we, and our families, are benefitting by having three—a pediatric early care support program, a perinatal, and a pediatric hospice program—with a dedicated pediatric staff, so that whatever the child/family needs and wherever they are in their journey, we are that anchor of support and care they need to take the next transitory step, wherever it may lead.

These programs are funded mainly by donations. In 2014 the Anchors Programs for Children received a donation of a half a million dollars to keep and expand the Anchors Pediatric Program. The Anchors Program also has many other donors that contribute to the program. To be good stewards to all donors, an annual report is completed that details how every dollar is spent. Fundraising for the Anchors Program never stops. The Anchors Program continues to expand. This year we added a robust educational series. This is an eight-part series directed at teaching not just pediatric staff but all staff that would encounter pediatric patients. This education series was completed by staff and volunteers and has been shared with more than 20 hospices across the country. The goal is to improve care not just for children on the Anchors Program but for any child receiving hospice care.

Dedicated Specialized Resources Help Bridge Diversity of Population Needs

Three dedicated programs tailored to specialized needs of our pediatric population allow us to provide what families need, when they need it, whether that be palliative support, perinatal hospice, or comprehensive pediatric hospice care for the child and his/her family. As noted, they also provide services that help transition and grow with the child and family as the baby/child ages and/or their needs change from palliative to hospice or more social-worked based to more clinically based. Whatever arises, we have a program and staff who can help.

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WALKING HOME: A 25-YEAR JOURNEY AT CANUCK PLACE CHILDREN'S HOSPICE

Debbie Butt

Director, Communications, Marketing & Events
Canuck Place Children's Hospice
Vancouver, BC, Canada
debbie.butt@canuckplace.org

Over one-quarter of a century ago, an exemplary pediatric oncology nurse in Vancouver, British Columbia, Canada, had a vision for better care for children who were terminally ill.

Brenda Eng believed that children needed an environment where their families could be with them in a home-like setting. She also knew, through her experience with children, that recreation, music and play therapy, counselling, education, memory making, and an integrated care plan could improve the journey for children with life-threatening illnesses and their families. She valued the relationship with patients and families and knew that relationships could also be a powerful instrument of healing in the face of suffering and uncertainty.

In the early 1990s, Eng embarked on a working trip to visit and observe one of the original pediatric hospices in England, Helen House. What she learned supported a notion she deeply believed: "We are on this planet to walk each other home. And that is really what the hospice is," Eng said. "I believe we can make it less lonely for children, less painful and less frightening. If we can support families through this, then I think that we have achieved something."

Eng also recognized that an innovative vision needed a team. She worked with pediatric nurse Betty Davies and together they wrote a plan and put together a first-line group to create a pediatric hospice. The team included the editor and publisher of the Vancouver Sun, Ian Haysom; a partner in the largest ad agency in BC at the time, George Jarvis; and finally a team member that would prove to be crucial years later: the owner at the time of the National Hockey League's Vancouver Canucks, Arthur Griffiths.

The group became known as HUGS (Human Understanding, Growth and Sharing) Children's Hospice Society.

After several years of fundraising by HUGS, the Vancouver Canucks, and a \$1CDN dollar-a-year lease from the City of Vancouver, renovations began to transform a stately mansion, Glen Brae, in a neighborhood called Shaughnessy.

In 1995, Canuck Place Children's Hospice opened as North America's first free-standing children's hospice. Today, Canuck Place has two hospices located in Vancouver and Abbotsford serving over 800 children and families in BC and the Yukon.

"Brenda's original vision, to create North America's first free standing pediatric hospice, and to care for children and families in need, remains at the heart of all we do," said Dr. Hal Siden, Medical Director of Canuck Place Children's Hospice. "We are the pediatric palliative care provider in the province of BC and provide eight family suites and 13 patient beds and an exceptional team of specialized clinicians."

Canuck Place provides medical respite, complex care in-home, pain and symptom management, music and recreation therapy, art, education, end-of-life care, and grief and bereavement counselling. The program is provided at no cost to families. On average, a child will be on the program for seven years. Parents and siblings remain on the bereavement program on average for three years following the death of their loved one.

Unlike typical Canadian hospitals, government funding only covers approximately 40% of annual operating expenses. That means more than half is covered by generous donors. The critical impact donors have on the lives of children and families cannot be understated. Not only did the NHL team share their name, but the Vancouver Canucks also became annual funders to the care provided by Canuck Place through their charitable foundation, Canucks for Kids Fund (CFKF).

“All of us were inspired by the original concept of Canuck Place and knew from the start we wanted to help bring this idea to life,” said Alex Oxenham, Executive Director of CFKF. “It’s been a privilege to share our name with such a special organization and to meet some of the heroic kids who have been on the program. Whether it’s hearing from the caregivers, decorating the house for the holidays, bringing the families for a skate at our rink, or indulging in a famous cookie, our board, staff and players feel an innate connection to the hospice and are always inspired to do more.”

Funds are raised for the hospice by the hockey club through team- and player-attended events including the Dice & Ice Gala, The Jake Milford Golf Tournament, Canucks SuperSkills, and 50/50 draws held at each home game with fans. A portion of these funds are granted to Canuck Place annually and represents 4-6% of the overall operating budget.

“Canuck Place has shown us that there can be joy found in the midst of tragedy,” said Oxenham. “That everyone deserves a full life, no matter how short or how long it is. We have learned how much memories matter, how generous the clinical team is with their love and compassion, and how strong and brave the children and families are.”

The hockey club’s support extends beyond the consistent and annual grants, which over 26 years amount to over \$30 million. The team brings moments of joy and memories that families hold dear. Those moments are when a patient meets FIN the team mascot for their first time. It is the Vancouver Canucks staff spending their day at the hospice helping to put up holiday lights. It is the magic of a family meeting their hockey heroes and spending an afternoon carving a pumpkin for Halloween. For over 26 years, CFKF has lifted the hearts of children and families in challenging circumstances and provided opportunities for crucial memories to be made.

Building long-term partnerships with a not-for-profit brand and an organization begins with understanding what values align between the entities. Identifying these shared values, discussing how working together could benefit partners, and crafting a 3–5-year partnership with achievable targets and outcomes is critical. This partnership agreement would include benefits and activations that are the responsibility of both partners. For example, a charity may need annual grants or awareness to support fundraising. The corporate partner could be looking for employee engagement through volunteer or match fundraising activities, employee attraction and retention, brand awareness through events, media and digital media opportunities, and opportunities for clients to learn more about the social responsibility of the company. One of the great brand strengths and benefits of the Vancouver Canucks

partnership with Canuck Place is the hope brought to children and families because players, alumni, coaches and staff support and value the journey families are facing.



Canuck Place keeps families like the Letchers together during uncertain times so no moment is missed. The Vancouver Canucks hockey team bring hope and incredible memories for this family.

Canuck Place RN, Doreen Landry, has been with Canuck Place since the doors opened with the vision of Eng and support of the Vancouver Canucks. In that time, through the leadership of a board of directors and a talented team, Canuck Place has become a clinical leader in pediatric palliative research. The organization also built a second hospice location in Abbotsford, created a 24-7 Care Line for families in urban and remote areas, formed a talented fundraising team and strategy, formalized knowledge translation and family advisory council to inform care, and expanded their in-hospital consultation and in-home patient care.

While growth and change have been a constant, one thing has never changed in Doreen's 26-year dedication to the original vision of the pediatric hospice: compassion and love for the children and families that walk through the front doors of the hospice.

"I see my role to be one of journeying with families, using my skill set in a way that makes their load feel lighter and easier to bear," said Doreen. "Perhaps most importantly, I want to ensure families don't feel alone in their most difficult moments."

The illness and death of a child is a life-altering experience and impacts the whole family. Grief doesn't have a timetable and is a highly individual journey. Canuck Place counsellors understand this and help families cope and find the courage to face the unknown, so no moment is missed. The Canuck Place counselling program includes individual and family counselling, music and play therapy, bereavement and spiritual care counselling, and social work. They also provide support and connection through sibling, parent, and grandparent support groups.

This integrated approach while a child is living and after the child has passed is crucial for families and part of the journey of care. “I have often said that one of the hardest parts of having a terminally-ill child is having the knowledge of that diagnosis,” said Canuck Place mom Kerena Letcher. “And then you have to continue to live day after day, providing care, and trying not to let the uncertainty suffocate you. I don’t know what we would do without Canuck Place. They have helped us make some of the most amazing memories over the years as a family, all while helping our 10-year-old son, Heston, maintain the best quality of life he could possibly have. Many of our cherished memories as a family are around the Vancouver Canucks and our time with Canuck Place.”

Since 2015, Canuck Place has seen a 34% increase of children and families requiring pediatric palliative care and a 94% increase in outpatient care. Canuck Place empowers children and families’ important, real choices: a choice for the place of care, a choice for the place for end-of-life, and a choice for emotional and bereavement support.

Canuck Place mom Katie Jamieson articulated how the support for the journey for a family continues 26 years after Eng brought her vision to life. “Canuck Place is palliative care in its purest form, there is space for everyone,” Jamieson said. “The child that lives within the walls for medical respite, the children that pass away after long battles, and the child that is gone only hours after arriving. When you enter the doors of Canuck Place as a parent with a living child, it can feel terrifying. The mere fact that you are there means the end is coming. That’s a terribly difficult sentence, but it holds a lot of truth. A family receiving care at Canuck Place Children’s Hospice is there to learn about, and tend to, the letting go of their child.

“What could be a more important or a more enormous task in life? What effort could possibly need more support than what Canuck Place provides? Could there be anything more important than changing the way a family can let go of their child, or how that child is cared for at their absolute sickest? What a terrible place to need, but what a gift it was to go there.”

Brenda Eng understood the gift of supporting a family journey. She rallied the support of a professional hockey team to be in the service of human beings. For 26 years, Eng’s vision has thrived, evolved, and continues on one bold goal: to reach every family caring for a seriously ill child in BC & Yukon who needs help—and ensure short lives have the gift of great days.

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ENGAGING ORGANIZATIONAL LEADERSHIP IN ADVANCING SUSTAINABILITY FOR PEDIATRIC PALLIATIVE AND HOSPICE CARE PROGRAMS

Stacy F. Orloff, Ed. D., LCSW, ACHP-SW
Vice President, Innovation and Community Health
EMPATH HEALTH
Clearwater, FL
stacyorloff@empathhealth.org

After 31 full years of working in community-based pediatric hospice and palliative care, you would think I'd have the magic answer about how to sustain community-based pediatric programs. Indeed, by now one would hope we wouldn't even have to answer this question. Shouldn't organizations understand the value and importance of pediatric hospice and palliative care and commit to funding these important programs? Pediatric hospice and palliative care programs seem to be more prone to being discontinued based on the organization's bottom line as compared to other programs and services that treat adults.

Community-based pediatric hospice and palliative care providers are often told that caring for children is costly and the parent organization cannot afford to sustain a program that traditionally loses money every budget year. There are many reasons for these programs to be costly as compared to reimbursement options. Properly caring for pediatric patients requires specialized staff who are trained in caring for seriously ill children and their families. These staff may have a reduced caseload size, depending on the organization's pediatric census. Staff positions are usually budgeted by overall census and staff-to-patient ratios. Most community-based pediatric hospice and palliative care programs will have a lower pediatric census and lower staffing ratio as compared to their adult counterparts, thus being more costly positions for the organization. Pediatric durable medical equipment needs are different, and some organizations struggle to maintain their own inventory or have a reliable external vendor. Pharmacy needs are also different for children than adults.

There are reimbursement options for pediatric hospice care, although most per diem rates don't typically cover the cost of caring for children. There are few resources to pay for pediatric palliative care. Some states have successfully worked with their Medicaid offices to create waivers to pay for pediatric palliative care; however, most seriously ill children and their families have little access to community-based palliative care programs.

There is still good news. There are many national coalitions advocating for reimbursement changes on a state and national level. Policies need to be changed. Demonstration programs need funding. And children and their families still need to be cared for. So, what can be done now to positively impact patient care while the advocacy work continues? There are some approaches that can be implemented while simultaneously working on macro changes.

I have long noticed an important component missing in the sustainability discussions. The missing component is representation from organizational administrative leadership. Clinicians are the ones that typically get together to discuss lack of programs and services. These conversations alone won't impact organizational change. Clinicians should engage in discussions with their administrative leaders, thus

creating opportunities for dialogue about sustainability. I find that most administrative leaders respond well to connecting the need for services to the organization's mission/vision/values. It's important to assist our clinical staff in making the business case by "painting the picture" and connecting these stories with the positive impact on the organization. Clinicians have the passion for the work and can tell the stories like no one else. They need help in converting their passion and storytelling into a business plan.

Here are some ideas: Learn how to write a business plan. Understand how making a 'friend for life' with younger families helps your organization (they have many more years to actively engage with your care continuum, including your adult programs). Engage with your grant writing team. Consider donors that may be interested in donating to support pediatric programs. Invite administrative leaders to make home visits with you. Include them in some of the meetings where you're discussing the need for additional services. Above all, understand that clinicians and administrative leaders want the same thing—to provide access to care for those who need it the most. Everyone can, and should, work together to find ways to sustain a robust pediatric care continuum. Advocacy for state/national policy changes, grant funding, directed donor gifts, and the organization's annual budget are an excellent way to start.

Twenty-eight years ago, I moved from a clinical position to an administrative leadership role within my organization. I am proud to say that through a shared commitment to our organization's mission/vision/values, taking the initiative to do many of the things I've suggested, and engaging in storytelling and sound business practices, we have sustained a very robust pediatric care continuum. Consider who is missing in your conversations and find ways to engage them. It's not only possible, it's most likely probable that by effectively engaging with your administrative leaders, you can sustain a program.

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SUSTAINABILITY OF SELF AND STAFF

Jessica Sturgeon, MT-BC, HPMT
Music Therapist
Seasons Hospice and Palliative Care
Middlebury, CT
jsturgeon@seasons.org

At the beginning of 2020, individuals and families were making plans for their futures. They were working towards personal and professional goals, starting new projects and growing relationships with others. Many were fighting their own battles and hoping to continue forward in anticipation of change. In March, however, these paths were all altered as the world was attacked from an entity that wreaked havoc on all aspects of life.

Many trends arose during the global COVID-19 pandemic, both positive and negative. An increase in appreciation of family, increased time for many spent at home, and a shift in priorities were all examples of how the realities of the pandemic allowed for personal growth. Media began to finally focus on the idea of “self-care” and work-life balance. During a time of such incredible sadness and turmoil, there was also an amazing amount of flexibility and resiliency that rose above. However, there were also a myriad of limitations to this new way of life. As time progressed into 2021, stressors continued to rise and burnout became apparent. People began to take on new roles in telehealth and at home; caregiving became more and more difficult to both find and navigate as hospitals continued to function at maximum capacity; there was a global increase in anxiety and depression; and many, inclusive of health care professionals, began working obscene numbers of hours to keep up with demands.

According to data collected through the U.S. Bureau of Labor Statistics, there was a drastic and historic loss of employment in the year of 2020 and into 2021. In fact, it was the largest decline in nonfarm payroll employment documented since at least 2010 (U.S Bureau Labor Statistics). The data tell us that this new way of life was just not sustainable. In health care specifically, the trends related to sustainability have been very telling over the past two years as many left the medical community to pursue jobs with less stress and risk. Nationally, since the beginning of the pandemic there has been an influx of conversation surrounding mental health, work-life balance, and priorities, while health care professionals everywhere are left feeling and asking, “What about us?”

There is a desperate plea for a better sense of appreciation and understanding, increased compensation and benefits, and more supports to be put into place from all types of health care professionals. Front-line workers, once celebrated and loved by their communities for their dedication during the pandemic, are now in the center of political controversies. The increased stress in combating COVID-19, vaccines, mandates, and plain and simple burnout have all contributed to the seemingly impossible ability to retain staff.

The question now becomes, how do we as a health care community alter this trajectory to better sustain the passion, the staff, and the work itself? According to U.S Bureau of Labor Statistics (2020), health care led in shortage of supplies or inputs by 64% as compared to other establishments. Recent research and polling have cited a common denominator in regards to retention and sustainability — health care workers and professionals not feeling valued or heard. This would indicate that the first step

is, quite simply, to listen. Listen to yourself, your peers, your staff, and your community. When it first began its wrath, the pandemic taught so many of us to stop and appreciate who we are and who we have in our lives. Though somehow, as time progressed, we allowed ourselves to settle into complacency and the “new norm.” When we listen to what is happening it gives us so much more insight and information into what steps we can take moving forward. We need to better listen to ourselves to identify possible burn-out symptoms, to combat psychological and somatic triggers related to the pandemic, and to work towards better self-awareness of professional goals and needs. Listen to your peers as they ask for help or clarification. Hear staff as they indicate their emotional and physical fatigue without excuse or empty promise that “it will get better soon.” And listen as the community articulates what they need to feel safer without alternate agenda. Listen to the plans, hopes, and growth opportunities that will allow for more people to be served and supported in a comprehensive and ethical manner.

The next step once you listen and hear what others need is to then integrate better practices to highlight the accomplishments and hard work continually being done during this unprecedented time. Compensation is often viewed as a direct reinforcement of a “job well done,” but the capacity to provide an increase in compensation is not always an available option as the pandemic depleted many financial resources. A direct verbal acknowledgement of someone’s work or experience, however, can be extremely validating and is fiscally possible for all health care organizations and professionals. It provides a simple way to boost self-esteem and morale. A general statement such as “You all are doing great” does not allow for a specific expression of gratitude that many need to hear. Just as we individualize care plans for our patients and families, we should work towards individualizing the gratitude we express to our employees and peers.

Finally, and most importantly, is providing better supports for mental health to all health care staff. Sustainability starts in the self, which must be addressed and healed in order to move forward. Medical personnel and staff have experienced a great deal of trauma within the last two years. There have been documented increases in anxiety, depression, and suicide among all types of staff in this community since the onset of COVID-19. Each time a new strain is identified or a community is experiencing an uptick in cases, many are triggered to experience the stress and fear as if COVID-19 was happening for the first time all over again. By providing more accessible and affordable mental health resources, whether this is accomplished by allocating funds from existing budgets or working in conjunction with organizations to provide reduced-rate services, there is an inherent increase in success at identifying and treating those at risk and increasing sustainability of staff. This can be accomplished through locating and collaborating with local, existing supports that are already available and in place to assist with collective and individual traumas. Individuals or organizations specializing in CISD (Critical Incident Stress Debriefing), EMDR (Eye Movement Desensitization and Reprocessing), creative arts therapies, and pet therapy can be wonderful assets to utilize for staff. By incorporating mental health supports quarterly or semi-annually, personnel will have better access and understanding of coping and adapting with pandemic and work-related traumas. When staff feel their efforts and their mental health are valued, they feel sustained.

The positives that were highlighted so fiercely as the health care community rallied together at the beginning of the pandemic are still evident today. If those positive attributes can be harnessed towards constructive change in the workplace, light and success can still be achieved despite the existing hardships, changes, and trauma. As the saying goes, “You cannot pour from an empty cup,” so it is our job to find sources that can be tapped to keep the cups of our health care professionals full.

Resources

U.S. Bureau of Labor Statistics (n.d.). *2020 results of the business response survey*. U.S. Bureau of Labor Statistics. <https://www.bls.gov/brs/2020-results.htm>.

<https://suicidepreventionlifeline.org/>

<https://icisf.org/sections/education-training/>

<https://www.emdr.com/>

<https://www.therapydogs.com/alliance-therapy-dogs/>

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SUSTAINABILITY AND STATEWIDE PEDIATRIC PALLIATIVE AND HOSPICE CARE COALITIONS

Betsy Hawley, MA
Executive Director
Pediatric Palliative Care Coalition
Pittsburg, PA
betsy@ppcc-pa.org

A recent survey of Statewide Pediatric Palliative Care Coalitions (SPPCC) revealed a wide variety of sizes, shapes, and models of organization. Unsurprisingly, no one model stands out as the answer to sustainability concerns. In fact, all the SPPCC's surveyed indicated that sustainability is among their chief concerns. This article presents a national snapshot of SPPCCs as well as overview of the individual SPPCCs surveyed. While by no means comprehensive, these SPPCCs were chosen to reflect the different types of organizational models utilized across the country.

Based on informal collection of data, 29 states have reported having a SPPCC. This group consists of both formally established organizations and very informal groups of volunteers.

Of these:

- 11 have been formed in the past two years
- 3 represent a region (more than one state)
- 3 are standalone 501c3 nonprofits
- 8 work within the framework of a larger statewide organization
- 1 has institutional support
- 2 represent state agencies supporting PPC programs

Of the twelve SPPCCs surveyed, five work within the framework of a larger state organization. Three are aligned with their state hospice and palliative care organizations (Louisiana/Mississippi, Minnesota, and Georgia). In Connecticut, they operate as a pediatric sub-committee of the Connecticut Coalition for Serious Illness. Alliance Kids in Maryland is part of Hospice Alliance (a regional hospice coalition). The reported benefits of this type of model are many. First, is the assurance that the larger state organization has strong pediatric representation. It provides an easy framework for SPPCCs to organize. Most state organizations already host educational events or annual conferences, allowing an easy platform for peds education. Several SPPCCs report having administrative and lobbying support from the larger organization, along with the use of their website. Of those surveyed, this model has worked well for their SPPCC. This feedback indicates that a when forming a new SPPCC, checking in with already established state organizations would be an excellent first step.

The Greater Illinois Pediatric Palliative Care Coalition (GIPPCC) and the Pediatric Palliative Care Coalition (PPCC) in Pennsylvania are both 501c3 nonprofits and a volunteer Board of Directors serve as leadership. Both have paid staff and strong volunteer involvement. They both indicated that this model allows for maximum neutrality and therefore encourages a broad spectrum of stakeholders. Paid staff ensures that the mission and vision of the SPPCC are carried out and serves to keep volunteers engaged

and supported. Paid staff also necessitates fundraising! GIPPCC and PPCC both report that funding comes from foundation support, individual contributions, fundraising events, and earned income. While this takes time and effort, it also helps to raise the profile of pediatric palliative and hospice care in the community served.

The survey concluded with the open-ended question: What is your best tip for coalition sustainability?

- Identifying integral stakeholders within the region (parents, Medicaid, interdisciplinary professionals, etc.) and creating a platform that is easily managed to produce.
- Have an organization that is committed to it and will house it. Admin support is essential.
- We think the recent addition of some admin time will help a lot! We think starting slowly is important, so we don't burn people out, and also so we do things well to build rapport and trust.
- Ensuring that we are providing value to members, some structure for dues.
- Administrative support, diversified funding streams, broad-based stakeholder engagement.
- Try not to take on too many projects at once!
- Diversify funding sources! Encourage hospital/hospice financial support.
- Perhaps a million-dollar question...we are still working on it.

For the full survey data, please see the attached spreadsheet. You will also find the chart with all reported SPPCC's across the country. If you are not already involved with your state SPPCC, please feel free to connect with those listed. State champions are also listed for many states without a formalized coalition. If your state has a coalition (in any shape or form) and you would like to be included, please contact me.

A special thanks to all the SPPCC leadership that contributed to the survey for this article. [Download the survey results spreadsheet.](#)

Pediatric Palliative Care Coalitions and PPC State Champions Throughout the United States

State	Name	Contact	Website
Alabama	State Champion	Sam Perna, Birmingham VA Medical Center sperna@uab.edu Lynn Vaughn lynn.vaughn@childrensal.org	
Alaska	Northwest Pediatric Palliative Care Coalition: Alaska, Idaho, Montana, Oregon, Washington	Rebecca Weicht Graves Rebecca.WeichtGraves@providence.org	nwppcc@seattlechildrens.org
Arizona	Arizona Coalition for Pediatric Palliative Care	Tressia Shaw tshaw@phoenixchildrens.com Christy Torkildson Christy.Torkildson@gcu.edu	
Arkansas	State Champion	Kay Kirk, Arkansas Hospice kkirk@arkansashospice.org	

		Judy Wooten jwooten@arkansashospice.org	
California	Children's Hospice and Palliative Care Coalition	Christy Torkildson chpcc2021@gmail.com	
Colorado	State Champion	Brian Greffe brian.greffe@childrenscolorado.org Nancy King nancy.king@childrenscolorado.org	
Connecticut	CT Coalition for Serious Illness Care (Pediatric Comm)	Taryn Hamre Thamre@connecticutchildrens.org	
Delaware	State Champion	Carly Levy Carly.levy@nemours.org	
Florida	Florida Pediatric Palliation Consortium (consortium in formation)	Laura Drach Ldrach1@jhmi.edu	
Georgia	Georgia Hospice & Palliative Care Org (GHPCO) Children's Healthcare of Atlanta (CHOA)	Khaliah A. Johnson Khaliah.Johnson@choa.org Paula Sanders admin@ghpco.org	
Hawaii	State Champions	Jasmin Jensen jassjen@msn.com Jaime Sharpe jtsharp@hotmai.com	
Idaho	Northwest Pediatric Palliative Care Coalition: Alaska, Idaho, Montana, Oregon, Washington	Whitney Price, LCSW pricew@slhs.org Sean Timpane timpanes@slhs.org	nwppcc@seattlechildrens.org
Illinois	Greater Illinois Pediatric Palliative Care Coalition	Kristin James kjames@gippcc.org	www.gippcc.org
Indiana	State Champion	Caitlin Scanlon Cscanlon1@IUhealth.org	
Iowa	State Champion	Lane Moser lane.moser@unitypoint.org	

Kansas	Kansas Hospice and Pediatric Palliative Care Coalition	Kathy Davis Kdavis2@kumc.edu	
Kentucky	Kentucky Pediatric Palliative Care Coalition	Lindsay Ragsdale Lindsay.ragsdale@uky.edu	
Louisiana & Mississippi	Gulf States Pediatric Palliative Care Consortium	Alexis Morvant amorva@lsuhsc.edu Christian Paine cpaine@umc.edu	https://lmhpco.org/healthcare-professionals/pediatric-palliative-care/
Maine	State Champion	Allison Caldwell acaldwell@mmc.org	
Maryland (Mid-Atlantic region)	Alliance Kids	Mary Tiso mtiso@gilchristservices.org	www.thehospicealliance.org
Massachusetts	Pediatric Palliative Care Network - Massachusetts Dept. of Public Health	Jennifer Bates jennifer.k.bates@state.ma.us	www.mass.gov/ppcn
Michigan	Children's Palliative Care Coalition of Michigan	Ken Pituch kpituch@umich.edu	www.childpalliative.org
Minnesota	Pediatric Palliative Care Coalition of Minnesota	Jody Chrastek jchrast1@fairview.org	www.mnhpc.org/individuals/pediatric-palliative-care/ppccmn/
Mississippi/Louisiana	Gulf States Pediatric Palliative Care Consortium	Alexis Morvant amorva@lsuhsc.edu Christian Paine cpaine@umc.edu	https://lmhpco.org/healthcare-professionals/pediatric-palliative-care/
Missouri	State Champion	Joan L. Rosenbaum Rosenbaumj@wustl.edu	
Montana	Northwest Pediatric Palliative Care Coalition: Alaska, Idaho, Montana, Oregon, Washington	Fiona Sampey fiona.sampey@gmail.com	nwppcc@seattlechildrens.org

Nebraska	State Champions	Andrew McFadyen amacfadyen@childrensomaha.org Suzanne Haney kgates@procarehospicenv.com Sabrina Schalley sschalley@ChildrensOmaha.org	
Nevada	State Champions	Kathleen Gates kgates@procarehospicenv.com Angela Berg aberg@procarehospicenv.com	
New Hampshire			
New Jersey			
New Mexico	State Champions (coalition in formation)	Jennifer Bartz jenb@herospathpalliativecare.org Vizcarra Wurzel vizcarrawl@gmail.com	www.herospathpalliativecare.org
New York	Hospice and Palliative Care Association of New York	Kim Ryan kryan@hpcanys.org	https://www.hpcanys.org/
North Carolina	Pediatric Palliative Care Coalition of North Carolina	Allie Shukraft Allison.shukraft@atriumhealth.org Lily Gilmore lgillmor@transitionslifecare.org	
North Dakota			
Ohio	Ohio Pediatric Palliative Care and End of Life Network (OPPEN)	Lisa Humphrey lisa.humphrey@nationwidechildrens.org	
Oklahoma	State Champion	Rachna May Rachna-May@ouhsc.edu	
Oregon	Northwest Pediatric Palliative Care Coalition: Alaska, Idaho, Montana, Oregon, Washington	Bob Macauley macauler@ohsu.edu	nwppcc@seattlechildrens.org
Pennsylvania	Pediatric Palliative Care Coalition	Betsy Hawley betsy@ppcc-pa.org	www.ppcc-pa.org

South Carolina	South Carolina Pediatric Palliative and Hospice Care Collaborative	Brooke Johnston brookejohnston@mailfence.com	
South Dakota	State Champion	Dan Mark dwwmark@gmail.com	
Tennessee	Tennessee Pediatric Palliative and Hospice Care Collaborative	Tracy Hills tracy.hills@vumc.org Justin Baker Justin.baker@stjude.org	
Texas	Texas Pediatric Palliative Care Consortium	Jan Wheeler jan@joyandhope.org Melody Brown Hellsten mbhellst@txch.org	www.texasppcc.org
Utah	Utah Pediatric Palliative Care Coalition (coalition in formation)	Becky Oakley beckyoakley@bradesplace.org	
Vermont	Department of Health – Pediatric Palliative Care Program	Jessica Boyea lbarbaro@edmarc.org	http://www.healthvermont.gov/children-youth-families/children-special-health-needs/palliative-care
Virginia	State Champion	Laurie Barbaro lbarbaro@edmarc.org	
Washington	Northwest Pediatric Palliative Care Coalition: Alaska, Idaho, Montana, Oregon, Washington	Anne Anderson Anne.anderson@seattlechildrens.org	nwppcc@seattlechildrens.org
West Virginia	State Champion Hospice Council of West Virginia	Chris Zinn czinn@hospicecouncilwv.org	
Wisconsin	State Champions	Anne Marsh ammarsh@wisc.edu Alida Yee a.yee@uwhealth.org Catherine Stevens CStevens2@uwhealth.org	
Wyoming			

NATIONAL COALITION FOR HOSPICE AND PALLIATIVE CARE, PEDIATRIC PALLIATIVE CARE TASKFORCE, PAYMENT & FINANCING WORKGROUP

Melissa Hunt, PharmD, BCPPS
Pediatric Clinical Pharmacist
Optum Hospice Pharmacy Services
Montgomery, AL
melissa.hunt@optum.com

Financing a pediatric palliative care (PPC) program is complicated. Multiple contracts must be managed, all with different requirements. The contracting process is time-consuming and confusing. There is no standardization between programs, especially across state lines. Teams are full of uncertainty regarding what they can feasibly offer and how they will get paid. Many teams hesitate to even consider caring for pediatric patients because they are unsure if they will get paid for all their services. For these organizations to be sustainable, they need to have a secure payment and financing model. Access to PPC will improve when more organizations can afford to invest in and provide pediatric palliative care services. For these reasons, payment and financing is one of the focuses of the National Pediatric Palliative Care Taskforce.

Background on the PPC Task Force

A convening of national PPC leaders in 2019 identified the need for a pediatric-specific national task force to set field strategy and build field capacity. The intent of the PPC Task Force is to improve national alignment and impact by identifying feasible action items to accelerate advancement of the field and improve children's access to high-quality palliative care. The inter-professional membership is comprised of pediatric palliative care leaders from the National Coalition for Hospice and Palliative Care's 13 member organizations, the American Academy of Pediatrics (AAP), and family advocates. The work is generously funded by a two-year grant from the Cameron and Hayden Lord Foundation.

Pediatric Palliative Care Task Force

The Pediatric Palliative Care Task Force launched into 2021 with a guiding vision, clarity of mission, and demonstrative goals that will underpin our work moving forward. The Task Force has identified three key priorities to advancing the field of pediatric palliative care: (1) payment and financing; (2) assessment of need and capacity; and (3) raising of awareness and demand. The group will assess, initiate, and promote critical actions in these three domains to enhance and increase children's access to high-quality pediatric palliative care services.

Payment and Financing Workgroup

The payment and financing workgroup's overall mission is to *"Activate interdisciplinary collaborations with key payment & finance decision-makers and create real-world payment & financing solutions to continuously improve access to pediatric palliative care through financial sustainability."* Pediatric representation among key payment & finance decision-making stakeholders will allow for continuous improvement in pediatric palliative care sustainability. Access to pediatric palliative care will improve with more organizations able to provide services.

The payment and financing workgroup's ultimate goal is to develop an ideal payment and financing model, evaluate which states are meeting those standards, and work towards making them a reality in additional states including modifications to fit regional resources. The workgroup will support the efforts of Palliative Care Quality Collaborative (PCQC) to develop a pediatric state report card and then use this information in our endeavors. Evaluating current state payment & financing models will allow us to identify gaps in payment and develop solutions to overcome those barriers. The workgroup hopes to collaborate with Center to Advance Palliative Care (CAPC) in their efforts to develop a PPC payment and financing toolkit. Developing functional financing guides will allow more hospices to care for pediatric patients, therefore increasing access. Improving financial resources will allow for added resources and increased quality of care.

Recent steps include mapping the payment and financing experience from the child and family perspective to better inform a model of payment. The workgroup helped evaluate the state plan amendment proposal for the state of Illinois prior to approval and will continue to work with the Illinois coalition as they develop payment models and regulations. We will use this as a base to develop an ideal model that can be incorporated by other states.

The payment and financing workgroup is focused on providing solutions that allow increased access to pediatric palliative care. Ensuring adequate payment and financing for programs will improve sustainability. Ultimately, if organizations don't get paid, work doesn't continue.

If you have questions, suggestions, or would like to contribute to the work of the payment and financing workgroup, please reach out to the workgroup co-chairs Melissa Hunt (Melissa.hunt@optum.com) or Tressia Shaw (tshaw@phoenixchildrens.com).

For more information regarding the Pediatric Palliative Care Taskforce visit:

[Pediatric Palliative Care Task Force | National Coalition for Hospice & Palliative Care | National Coalition For Hospice and Palliative Care \(nationalcoalitionhpc.org\)](#)

Payment and Financing Workgroup members: Melissa Hunt (SPPCP) (Co-chair), Tressia Shaw (NAHC) (Co-chair), Holly Davis (NHPCO), Sarah Friebert (CAPC), Kristin James (PPC Coalition), Dannel Shu (FA), Terri Warren (CHA)

PPC Payment and Financing Workgroup Mission:

Activate interdisciplinary collaborations with key payment & finance decision-makers and create real-world payment & financing solutions to continuously improve access to pediatric palliative care through financial sustainability.

PPC Payment and Financing Workgroup Vision:

Create sustainability for pediatric palliative care to allow equitable access to high-quality pediatric palliative care for everyone.

PPC Payment and Financing Workgroup Goals:

- Establish a permanent presence of interdisciplinary pediatric palliative care leaders within the Coalition.
 - Establish pediatric representation among key decision-makers for payment & financing
- Continuously delineate key priorities to improve access to pediatric palliative care.
 - Evaluate current gaps in payment & financing to determine priorities for improvement

- Galvanize crucial stakeholders, organizations, and resources to continuously target these priorities.
 - Establishing pediatric representation within key decision-maker organizations will ensure pediatric concerns are at the forefront
 - Utilizing parent advocates will emotionally speak to the services needed and value added
- Forge ongoing collaborations across the field of pediatric palliative care to build capacity, align resources, and overcome barriers to pediatric palliative care.
 - Evaluate current resources each organization already has regarding payment & financing

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ITEMS OF INTEREST

In each issue of our Pediatric E-journal, we offer additional items of interest.

1. **NHPCO Palliative Care Online Resources:**

NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community–Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

2. **Pediatric Hospice and Palliative Care Resources:**

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org
- **NHPCO's Palliative Care Resource Series** includes pediatric palliative resources like:
 - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
 - *Consideration for Complex Pediatric Palliative Care Discharges*
 - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
 - *Nonpharmacological Pain Management for Children*
 - *Sibling Grief*
 - *Pediatric Pain Management Strategies*
 - *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*

3. **Trends in Pediatric Palliative Care Research**

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#). [View the New Citation List in their library](#).

4. **Pediatric Resource on Medication Coverage**

In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled [Determination of Hospice Medication Coverage in CHILDREN](#).

5. **Subjects and Contributors for Future Issues of This E-Journal**

We are currently discussing topics like bereavement, sibling support, and standards for our three remaining issues of 2022. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

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NHPCO

National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org