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Centers for Medicare & Medicaid Services
US Department of Health and Human Services
Washington, D.C. 20201

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Via Electronic Submission: healthychildrenandyouth@cms.hhs.gov

Re: Pediatric Alternative Payment Model Concepts

To Whom It May Concern:

Thank you for the opportunity to submit comments on designing a Pediatric Alternative Payment Model that will improve quality and reduce cost of care for children and youth enrolled in Medicaid and the Children's Health Insurance Program (CHIP). As the RFI notes,

"The aim of this model is to facilitate strategies for timely and appropriate delivery of family-centered, community-based, linguistically and culturally appropriate, cost-effective, and integrated services to all children and youth covered by Medicaid and CHIP with an emphasis on those with or at-risk for developmental, social, emotional, or behavioral health challenges, intellectual or physical developmental delays or disabilities, and/or those with complex and/or chronic health conditions (also known as "high-need, high-risk beneficiaries")." (emphasis added)

On behalf of the signatories below, the Center to Advance Palliative Care applauds CMS for taking specific steps that have the potential to improve quality care and wellbeing for high-need, high-risk pediatric populations. As such, our comments focus on seriously ill infants and children covered by Medicaid and CHIP who, together with their families, are coping with complex and potentially life-limiting conditions. These patients require access to pediatric palliative care to support their quality of life and ensure appropriate, family-centered care.

Background on CAPC and Pediatric Palliative Care (PPC)

The Center to Advance Palliative Care (CAPC) is a national organization dedicated to ensuring that all persons with serious illness have access to quality palliative care, regardless of diagnosis, setting of treatment, age, or state of the disease. Palliative care is an interdisciplinary, team-based model, which includes a physician, nurse, social worker, chaplain, and other healthcare professionals. It is focused on providing relief from the symptoms and stresses of serious illness, with the goal of improving quality of life for both the patient and the family.

Pediatric palliative care (PPC) is appropriate for infants and children with a wide range of complex conditions, and should be available regardless of prognosis – even when cure remains a strong possibility. PPC relieves suffering across multiple realms; improves the child's quality and enjoyment of life while helping families adapt and function during the illness and through bereavement; facilitates informed and value-based decision-making in the best interest of the child by patients, families, and health care professionals; and assists with ongoing coordination of care and communication among clinicians and across various sites of care.

The American Academy of Pediatrics recommends initiation of PPC at diagnosis and its integration throughout the illness course for all children confronting complex medical conditions.ⁱ This recommendation and the mounting evidence of quality and value (described in detail below) has led several states to enact Medicaid waivers covering pediatric hospice services concurrent with curative treatment without time limitations as a means of expanding access to earlier PPC (commonly called “concurrent care”).

Currently, there are more than 400,000 pediatric patients and families estimated to be living with life-threatening or serious health conditions in the US.ⁱⁱ Approximately 27 percent of children living with complex medical conditions have conditions that affect their activities usually, always or a great deal,ⁱⁱⁱ and an estimated 8,600 children with complex medical conditions are eligible for and would benefit from palliative care on any given day.^{iv}

Pediatric Palliative Care Ensures Value

Studies on the impact of PPC confirm that its delivery improves both quality of life and clinical outcomes while simultaneously reducing unnecessary – and often unwanted – Emergency Department (ED) visits and hospitalizations. PPC delivers significant quality improvements, as revealed in a study by the Dana-Farber Cancer Institute and the Boston Children’s Hospital which showed:^v

- Reduction in reported pain from 66% to 47%
- Reduction in dyspnea from 58% to 37%
- A trend toward reduced anxiety, from 58% to 39%

PPC has a similarly strong impact on parents. Parents of children with serious complex medical conditions at a hospital in Seattle reported significant improvements in health-related quality of life from baseline to post-PPC interventions.^{vi}

By reducing symptoms and stresses, PPC helps support caring for children in their communities and at home as they often prefer, giving families relief and alternatives to 911 calls, ED visits, and unwanted hospitalizations, and consequently results in substantial cost avoidance. A statewide concurrent care program for children in California achieved the following:^{vii}

- A nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3
- A significant drop in average hospital length of stay from 16.7 days to 6.5 days (more than a 60% reduction)
- A strong trend in reducing 30-day readmission rates, from 45% of admissions to 37%
- Net savings – after deducting program costs – of \$3,331 per enrollee per month.

These results are consistent with quality improvements and utilization reductions found for adult palliative care services; however, the impact of PPC is multiplied due to the positive effect on parents and other family members. Consider that as many as 17 million adults are caregivers for a seriously ill child.^{viii} In a significant number of cases, these parents will face decades’ long course of care supporting the affected child, as well as the rest of their family. Therefore, bolstering parents is vital not only to ensuring the best care of their children (including healthy siblings), but also to minimizing the secondary impacts on health status, employment, and income.

Lessons from Providers and Medicaid Managed Care to Inform Model Concept

CAPC convenes palliative care providers, as well as payers, from across the United States to identify best practices and disseminate those through tools, training and technical assistance. CAPC shares these lessons for CMS' consideration:

- Infants and children with serious illness who are eligible for hospice must be able to access hospice services concurrent with any disease-directed care, as is currently allowable under Section 2302 of the Affordable Care Act, aka "the concurrent care for children requirement." Alternative payment models must accommodate concurrent hospice care and treatment for those who are eligible. The experience in this model can also be used in fashioning other pediatric alternative payment models.
- Pediatricians and key pediatric specialists should be incentivized to get additional training in core palliative care skills, including assessment and treatment of pain and other symptoms, and communication (especially skills in clarifying values and goals, and conveying illness expectations along with the full range of treatment options).
- Infants and children with serious, complex medical conditions should be proactively identified for formal assessment of symptom burden, caregiver burden, and other concerns. This can be done through EHR triggers and claims algorithms.
- Moderate- and high-need families should have prompt access to PPC specialists. PPC teams must be available in pediatric practices and clinics as well as in hospital settings.
- An effective way to ensure access is to make pediatric hospice services available to all families facing serious, complex medical conditions, and to allow such services to be provided concurrent with curative treatment and regardless of prognosis.
- Pediatric performance measures should incorporate evaluation of access to and utilization of PPC services in some manner. Rates of PPC utilization for the target population would be an effective performance measure, as well as rates of ED utilization among infants and children with serious, complex medical conditions.
- PPC teams should be paid via alternative payment arrangements such as fixed case rates (PMPM), rather than fee-for-service, due to the significant time commitments, unbillable team members, and need for 24/7 coverage. Within the context of a pediatric alternative payment model, services for infants and children with serious complex medical conditions should be priced at a level high enough to enable co-management by a PPC team.

Conclusion

We encourage CMS to ensure access to pediatric palliative care in the pediatric alternative payment model. As described, this can be done through mandatory model requirements and/or inclusion of quality measures around access to PPC, along with sufficient payment for the target population to support co-management by a PPC team.

Thank you again for the opportunity to submit these comments. Please do not hesitate to contact myself or Stacie Sinclair, Senior Policy Manager at Stacie.Sinclair@mssm.edu if we can provide any additional detail or assistance.

Sincerely,



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Director

Center to Advance Palliative Care

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This letter is endorsed by the leaders and organizations below:

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- ⁱ R.M. Nelson, J. Botkin, E.D. Kodish, et al. Palliative care for children, *Pediatrics*, 106 (2000), pp. 351-358
- ⁱⁱ Xu J, Murphy SL, Kochanek KD, Bastian BA. Centers for Disease Control and Prevention. Deaths: Final Data for 2013 (64) 2 (February 16, 2016)
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- ^{iv} National Hospice and Palliative Care Organization. ChiPPS White Paper: A call for change: recommendations to improve the care of children living with life-threatening conditions. October 2001
- ^v Wolfe, J, Hammel, JF, Edwards, KE, et al. Easing of suffering in children with cancer at the end of life: Is care changing? *Journal of Clinical Oncology* 2008, 26(10), 1717-1723.
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- ^{vii} Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. *Journal of Palliative Care and Symptom Management*, 2016; 52(3)
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