

GULF STATES PEDIATRIC PALLIATIVE CARE CONSORTIUM (GSPPCC)

Formed in January 2019, originated within the Louisiana Mississippi Hospice and Palliative Care Organization (LMHPCO)

Vision: All children and families in the gulf states region facing serious illness will have access to comprehensive support through the entire duration of serious illness both in the hospital and the home with the goal to prevent, anticipate and mitigate suffering in all its forms.

Broadly interdisciplinary with comprehensive representation throughout the state, including several premier pediatric hospice agencies and inpatient pediatric palliative care programs as well as nine different disciplines

MEDICAID'S CONCURRENT CARE HOSPICE BENEFIT LANGUAGE

In the first months of GSPPCC's existence, a needs assessment of its community showed that the GSPPCC's focus should start backwards, beginning at end of life and working towards improving upstream palliative care efforts within Louisiana (LA) and Mississippi (MS). Given results from the needs assessment, the preliminary focus was to transform pediatric hospice care in LA.

Coincidentally, in March 2019, GSPPCC learned from a local hospice program that the language describing the pediatric concurrent care hospice benefit in the Medicaid manual had been changed. This subsequently inspired a thoughtful dialogue within the LA hospice community.

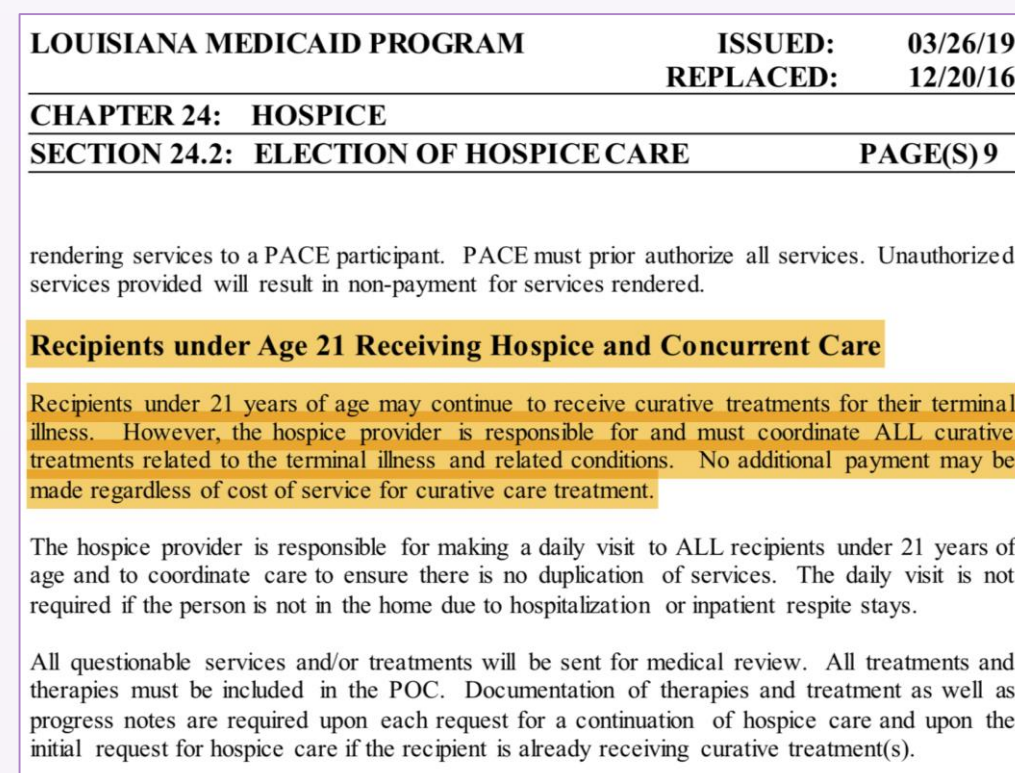


Figure 1. LA Medicaid's Concurrent Care Hospice Benefit New Language in 2019

CONCERNS

- Heavy cost burden for hospice agencies
 - Responsible for extraordinarily expensive reimbursement for care plan entities such as chemotherapy, seizure medications, hospitalizations, DME, and subspecialty visits.
 - Risk of audits
 - In LA, hospice per diem is roughly \$150-190 per day per patient.
 - Could quickly lead to bankruptcy
- Potential to decrease the utilization of hospice for seriously ill children in the state of LA.
- Many children might unnecessarily suffer.

Fortunately, despite these worries, no hospice agencies were denied payment nor were any audits conducted.

Of note, the fear of the implications of this language did cause hospices to limit the number of patients receiving concurrent care or discharge sooner than normal, anecdotally.

ACTION STEPS

LMHPCO met with Governor John Bel Edwards' office to discuss concerns about the new Medicaid language guiding concurrent care in LA. Governor Edwards' office supported and encouraged the consortium to rewrite the language.

In partnership with local hospice agencies and LMHPCO, the GSPPCC led an incredible community-wide effort which drafted >12 new versions of what a concurrent care model could look like in LA.



Figure 2. Collaborators

Chapter 35. Recipient Eligibility, §3503. Waiver of Payment for Other Services

- Hospice providers must provide services to beneficiaries that are comparable to the Medicaid-covered services that could have been received prior to the election of hospice. This requirement refers to all Medicaid-covered services including, but not limited to, durable medical equipment, prescription drugs, and physician-administered drugs.
- Beneficiaries who are age 21 and over may be eligible for additional personal care services as defined in the Medicaid State Plan. Services furnished under the personal care services benefit may be used to the extent that the hospice provider would otherwise need the services of the hospice beneficiary's family in implementing the plan of care.
- Beneficiaries under age 21 who are approved for hospice may continue to receive life-prolonging treatments. Life-prolonging treatments are defined as Medicaid-covered services provided to a beneficiary with the purpose of treating, modifying, or curing a medical condition to allow the beneficiary to live as long as possible, even if that medical condition is also the hospice qualifying diagnosis. The hospice provider and other providers must coordinate life-prolonging treatments, and these should be incorporated into the plan of care.
- Beneficiaries under the age of 21 who are approved for hospice may also receive early and periodic screening, diagnostic and treatment personal care, extended home health, and pediatric day health care services concurrently. The hospice provider and the other service providers must coordinate services and develop the patient's plan of care as set forth in §3705.
- For beneficiaries under the age of 21, the hospice provider is responsible for making a daily visit, unless specifically declined by the beneficiary or family, to coordinate care and ensure that there is no duplication of services. The daily visit is not required if the beneficiary is not in the home due to hospitalization or inpatient respite or inpatient hospice stays.

Chapter 43. Reimbursement, §4315. Life-Prolonging Treatments for Beneficiaries under the Age of 21

- Reimbursement for life-prolonging treatments is separate from hospice payments and is made to the providers furnishing the services.

Figure 3. New proposed language

ADVOCACY SUCCESS

Our new language was submitted in December of 2019. In August of 2020, LAC 50:XV.3503 became intended for amendment and 4315 became intended for adoption November 9, 2020.

GSPPCC has been working closely with the Louisiana Medicaid office to roll out and implement the new language.

Working hand and hand with the LA Medicaid office, our next step is to create a policy that describes how to practically translate this legal language and incorporate it into our daily practice.

Unfortunately, once the pandemic occurred, like most things, our progress was slowed. We are motivated to continue this work during and after the pandemic in order to ensure that all seriously ill children in LA have access to quality hospice care and life-prolonging treatments to help them live as well as possible.

LESSONS LEARNED

- **Creating a platform for dialogue with the pediatric hospice and palliative care providers within your state is key. Learn from their experiences.**
 - If it were not for the creation of our consortium, we may have never learned of these Medicaid changes.
- **Be courageous, put yourself out there and go meet your state's leaders.**
 - Form a relationship with your state's leaders in order to effect change. The first step is simply introducing yourself.
- **Identify your state's growth opportunities.**
 - A thorough needs assessment is crucial. You must know where you are in order to understand where your state can go in the future.
- **Be vulnerably courageous.**
 - Even though you may feel like others might be more knowledgeable and qualified to lead, **imposter syndrome must be understood and diminished.**
- **Diversify the group at the table.**
 - Understand the importance of a diverse group at the table. **Multiple disciplines and diverse backgrounds are needed** to fully unpack all of the elements that affect the care of seriously ill children.
- **Focus on the patients' stories.**
 - Remember that **your patients' stories are very important when it comes to advocating for them.** Stories are more compelling than all the policy writing in the world.

CONTACT INFORMATION & DISCLOSURES

Please send questions to Pediatrics@LMHPCO.org

The authors have no financial relationships to disclose.

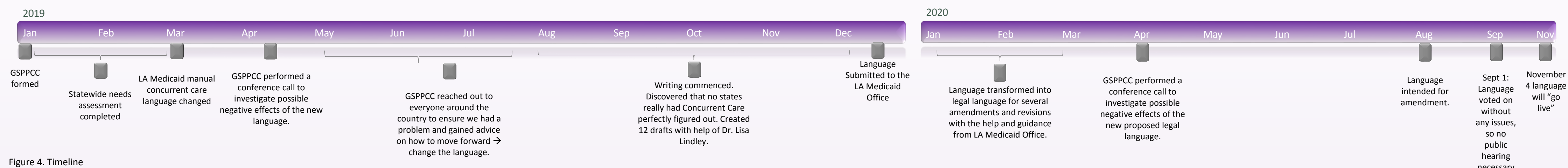


Figure 4. Timeline