CONCERNS

- Heavy cost burden for hospice agencies
  - High expenses due to the high number of patients
  - High costs for medications, equipment, and supplies

- Risk of audits

- Lack of reimbursement
  - Insufficient reimbursement for hospice care

- Potential to deplete the utilization of hospice care 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 hospice to limit the number of patients receiving concurrent care or discharge sooner than normal, anecdotally.

ACTION STEPS

- **LMHPPO 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 LMHPPO, the GSPPCC led an incredible community-wide effort which drafted >12 new versions of what a concurrent care model could look like in LA.

ADVOCACY SUCCESS


GSPPC 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 get to know 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, impostor 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@LMHPPO.org. The authors have no financial disclosures to report.