In December of 2008, in accordance with AB1745, the Partners for Children Palliative Care Waiver Program was implemented in an effort to provide families with chronically-ill and medically fragile children with in-home supportive services. The goal of these services focused on reducing both emergency room visits and the length of hospitalizations. With the State of California’s recent decision to terminate the Partners for Children Palliative Care Waiver Program, many patients and families are at risk of losing necessary services that have provided support, care coordination, pain and symptom management, expressive therapies, family counseling, and family training. These critical services have proven to be effective in reducing ED visits, hospitalizations, and mitigating psychosocial crises.

As a result of the program’s success, state lawmakers passed SB1004, which will allow for pediatric palliative care to continue; however currently under this bill it does not directly support reimbursement from the managed care providers for expressive therapies. This has created an opportunity to effectively structure a long-term sustainable outpatient pediatric palliative care program with a similar structure that can accomplish similar goals to the Partners for Children Waiver Program.

**OBJECTIVES**

- Identify the gaps between the current Pediatric Palliative Care Waiver (PPCW) that is ending and SB1004’s program structure
- Identify barriers in creating a long-term, sustainable, and comprehensive community-based pediatric palliative care program (CBPCC)
- Measure caregivers’ perceptions of the impact expressive therapies have on their child’s quality of life and mental health to justify the ongoing need for expressive therapies
- Offer creative solutions for organizations to continue offering similar services at low to no cost

**SERVICE GAPS AND CREATIVE SOLUTIONS**

- Services funded via private insurance and Medicaid managed plans under SB1004
  - Medical Doctor or Nurse Practitioner (MD/NP)
  - Registered Nurse (RN)
  - Licensed Clinical Social Worker/Associate Clinical Social Worker (LCSW/ASW)

- Services to be provided via contracts with community partners (hospitals, universities, etc.)
  - Massage, Music, Child Life, and Art therapies
  - Psychosocial family support (parents, siblings, extended family, etc.)

**BARRIERS AND GAPS**

- Fee-for-service payer model is not financially robust enough to provide a high-quality comprehensive CBPCC
- Expressive therapies (music, art, child life, and massage therapies), care coordination, and psychosocial family support are not reimbursable under most managed care plans
- SB1004 does not recognize expressive therapies as a critical reimbursable component of CBPCC
- Limited referral sources due to a lack of understanding of CBPCC

**CONCLUSION AND FUTURE CONSIDERATIONS**

Multidisciplinary care teams in collaboration with community partnerships with local hospitals, universities, and community agencies are the foundation for a successfully structured outpatient pediatric palliative care program. Pediatric palliative care education as well as program outreach are key to a programs success in receiving referrals. The current state-funded waiver program structure has key components that are not included in the new CBPCC under SB1004. Expressive therapies are perceived by caregivers as an integral component of a CBPCC, therefore creativity is critical in maintaining these services as part of a CBPCC.

Further research in the field of massage, art, music and child life therapies and its direct impact on the pediatric population within palliative care is necessary to be able to secure future funding (both for state and private insurance pay sources).

**REFERENCES:**