Leadership and Organizational Support for Pediatric Palliative Care in California and CCCC’s Future Role
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ISSUE
Leadership of California’s Pediatric Palliative Care (PPC) community and the best organizational structure to support the community’s current and future needs.

BACKGROUND
Prompted by funding challenges in 2015, the Children’s Hospice and Palliative Care Coalition (CHPCC) approached the Coalition for Compassionate Care of California (CCCC) about closer collaboration, which resulted in CHPCC becoming a division of CCCC. Since then, CCCC has worked hard to honor the spirit and meet the needs of the pediatric palliative care (PPC) community.

Today, the PPC field in California is in a natural transition phase. As part of its own strategic planning, the CCCC Board of Directors began to question whether CCCC was in a position to best meet the needs of the PPC community. To help inform their decision-making, CCCC sought feedback from the PPC community regarding current and future needs of the community and commissioned a survey and set of interviews with members of the pediatric community.

RESEARCH & FINDINGS
Survey
An 18-question online survey was developed and distributed by CCCC via e-mail to 1,100+ individuals who have expressed interest in PPC. The survey was open for three weeks, with three follow-up e-mail reminders sent. While the response rate of 5% was lower than anticipated, those who did respond provided a broad representation of key stakeholders, including clinicians, community service providers, educators, and parents.

Key findings from the survey were:
- Respondents felt that the most important activities that a PPC coalition should engage in are:
  1. Policy and Regulation: Initiating change in policies, regulations, and programs that increase seriously ill children’s access to community-based health services;
  2. Leadership: To promote open, integrated discussion on relevant issues and encourage wide participation of diverse stakeholders; and
  3. Education: To improve workforce capacity through educational opportunities for providers to gain skills around PPC service delivery.
- When asked about the number of staff a coalition might need to perform this work, the majority of respondents (62%) indicated at least two full-time staff.
- By a slim margin, respondents felt the needs of the PPC community would be best served as a division of a larger coalition devoted to palliative care more broadly (43%) versus those who felt the needs would best be met as a separate and independent organization devoted to PPC (40%).
- When asked about the most likely sources of funding PPC coalition work, “doing as much as you can through volunteer and in-kind efforts” was the top choice; grants and donations were tied for second place followed by membership dues.
Interviews
Thirteen stakeholder leaders participated in one-on-one interviews with the understanding that all comments would be reported anonymously. The interviews were conducted by an independent contractor with no direct ties to the PPC community or CCCC.

Priorities: Interviewees expressed a broad set of priorities for PPC, influenced by their professional role. Clinical leaders prioritized improving access, referrals, and reimbursement, while executive leaders prioritized advocacy and awareness. Three strong common themes arose:

1. Increasing awareness of the benefits of PPC by legislators, providers, payers, the health care system, and family members with seriously ill children;
2. Increasing access to PPC by increasing the pool of providers with the necessary skills and through ongoing education; and
3. Addressing the inadequacies in California’s implementation of SB 1004.

Coalition Role: When asked how a statewide coalition could help meet identified priorities, common themes included statewide advocacy on a legislative agenda, supporting awareness and access to PPC, developing and providing consistent educational events, and getting stakeholders together frequently for networking either at the state or regional levels.

Structure: When asked about the best structure for a PPC coalition, interviewees shared views on the pros and cons for a stand-alone structure versus being part of a larger organization. A stand-alone coalition focused on PPC could more easily pursue its own agenda, keep a narrow focus, and maintain a cohesive network. However, that structure would be expensive to start up and to maintain. Integrating a PPC coalition into another organization could provide broader reach and potentially have better access to “power.” Efficiencies around shared administrative and overhead costs can be achieved under this model; however, the agenda of a PPC coalition can get lost in a larger organization.

When asked how to achieve the most effective structure for a PPC coalition, the discussion centered around finding a leader passionate about pediatric palliative care who could create an inclusive process focused on collaboration with stakeholders.

CONCLUSION
Based on the findings from the survey and interviews, the CCCC Board of Directors believes that CCCC is no longer the best home for the PPC coalition.

NEXT STEPS
This doesn’t mean that CCCC feels it has no future role in supporting PPC. CCCC will continue to support PPC through activities that are a natural component of its broader work, including POLST for pediatrics and pediatric decision aids. CCCC will also continue activities that facilitate cross-pollination between pediatric and adult providers, including providing pediatric content as part of CCCC’s Annual Summit and promoting pediatric education opportunities for adult-focused providers. CCCC will continue to work toward its vision that Californians of all ages are able to live well in the face of serious illness.

While CCCC is committed to participate in and support the transition of the PPC coalition to its new home, we believe that leadership of this transition process must come from within the pediatric community. We look forward to working with the PPC community moving forward.