

Open Letter to the Pediatric Hospice & Palliative Care Community

Tuesday, 10 November 2020

Today, more than 10 years since the passage of the 2010 Patient Protection and Affordable Care Act (ACA), the survival of Concurrent Care for Children (Section 2302) is in question again. On this day, November 10, 2020, the Supreme Court opens arguments on *California v. Texas* – the outcome of this case will determine the fate of the ACA. A Supreme Court decision will be approximately 2 to 3 months after the case. What is unknown is how this might impact pediatric concurrent care. We expect that if the ACA is dissolved, Section 2302 will also be dissolved.

More than 8,000 children use hospice care each year in the US. Among the children on Medicaid and CHIP (and TRICARE), their receipt of concurrent care – simultaneous treatment for the terminal illness while enrolled in hospice – has grown from 30% to over 70% in recent years. In other words, children and their families increasingly see the value of concurrent care at end of life. How will you and your state respond to these families if Section 2302 is no longer available? While we acknowledge that there has been significant challenges and variation in state implementation of concurrent care, this is a national call for action to work with your state end-of-life community (e.g., children’s hospitals, hospices, state-level hospice and palliative care associations, legislators, and Medicaid Offices) to Make-a-Plan. We offer some recommendations for short- and long-term consideration:

Options

- **Private insurance** – Call private insurance payers. Private insurance is increasingly covering pediatric concurrent care. If your patient is covered by private insurance, a call to the provider to ask if they will cover is an easy step. For those children on Medicaid or CHIP only, a conversation might occur with the parents about adding children to a private insurance plan. Many businesses have Benefits Open Enrollment during this time and now might be an opportunity for families to add the child to their plan.
- **Open access hospice** – Identify the hospices in your community that provide open access hospice, which mirrors concurrent care, might be an option for these children if they are enrolled in the hospice or could transfer to this hospice.
- **Grant/philanthropy resources** – Check on whether there are temporary financial resources at your organization to cover the gap in service that would occur if there is no concurrent care.
- **Medicaid Early & Periodic Screening, Diagnostic, and Treatment (EPSDT)** – Explore Medicaid EPSDT. Work with your state Medicaid Office to add concurrent care as a designated EPSDT service for children.
- **Legislation** – Legislate pediatric concurrent care. A long-term option is to legislate concurrent care through a state-level bill. Some states allow for legislative changes to their Medicaid program. A conversation with your state hospice association legislative representative might provide guidance on your specific state options.

We are running out of time. We now need action. We encourage you to gather key stakeholders and start these conversations about what will happen if children in your state lose concurrent care

services. Make-a-plan and be ready to offer solutions to your state Medicaid Offices. We are here to work with you and thank you for your efforts. Please visit our site for updates.

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