

2020 Make-a-Plan Campaign

The make-a-plan campaign encourages you to prepare if Concurrent Care for Children is struck down by the US Supreme Court. Section 2302 is a short but defining provision within the ACA that has dramatically altered the critical medical and emotional services available for children and their families coping with a life-limiting condition. A coordinated response generates solidarity in messaging that underscores the impact of the ACA. Share stories about the benefits of Concurrent Care for Children as well as the risks of harm for repealing the ACA. Speaking about first-hand experiences and insights at a patient-, provider-, advocacy/coalition-, and state/policy-level will create greater awareness. Stakeholders can be prepared by reflecting on unique experiences, aligning with others' stories, and by thorough knowledge of the implication on this issue of ACA Section 2302, Concurrent Care for Children

- The 2010 Patient Protection and Affordable Care Act (ACA) was passed by the US Congress and signed into law on March 23, 2010.
- ACA Section 2302, called Concurrent Care for Children mandated concurrent hospice care along with medical treatment for seriously ill, Medicaid/CHIP children under 21years. It has been law for 10 years.
- Concurrent Care for Children was decades in the making. Child advocates field tested the principles of concurrent care prior to ACA. Demonstration projects were conducted in the 1990s around the US in place like Colorado, California, and Florida to assess the feasibility and acceptability of providing both medical treatment and hospice care for children.

[Concurrent Care & ACA - Open Letter REVDDownload](#)

[Concurrent Care & Supreme Court - Talking PointsDownload](#)

[Concurrent Care & Supreme Court - Fact SheetDownload](#)

What We Know

- Medical advances have improved life expectancy for children with cancer, and yet more than 30,000 children die each year of health-related problems.
- More than 8,000 children use hospice care each year in the US.
- Among the children on Medicaid and CHIP, their use of concurrent care has grown from 30% to over 70% in recent years. (est. total usage since enactment =20,000).

The Problem

- The court case California v. Texas is scheduled for ACA argument before the Supreme Court of the United States on Nov. 10, 2020. Changes to the ACA such as repealing the Act could eliminate Concurrent Care for Children and cause detrimental harm to children at end of life.
- A Supreme Court decision will be approximately 2 to 3 months after the case.
- The possible demise of the Concurrent Care for Children provision reminds us that parents should never have to choose between hospice and hope for a cure for their kids.

What We Know

- Medical advances have improved life expectancy for children, and yet more than 30,000 children die each year of health-related problems.
- More than 8,000 children use hospice care each year in the US.
- Pediatric hospice care is still underutilized (~27%).
- Among the children on Medicaid and CHIP, their use of concurrent care has grown from 30% in 2013 to over 70% in 2018. (est. total usage since enactment =20,000). Without concurrent care, most of these pediatric hospice patients would drop hospice care as these families would not choose to give up treatment to have hospice services.
- Pediatric concurrent care is not uniformly covered by private insurance.
- Adult concurrent care is currently being piloted in Medicare.

What We Can Do

- Private insurance – private insurance payers are 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 – identifying 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 – checking 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) – an option might be to work with your state Medicaid Office to add concurrent care as a designated EPSDT service for children.
- Legislation – 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.

Benefits of Concurrent Care

- Concurrent care has decreased the number of ED visits and hospitalizations by 50% in some locations.
- Children and their families no longer must forego available treatments to fight illness to have an inter-disciplinary team providing medical, emotional, practical and spiritual support at home.
- Patient-centered care.
- Patient decisions that are based on the latest clinical research and information.
- Services and supports given changing and increasing prognostic uncertainty.
- Close contact with the insurer (Medicaid).

- Facilitates a joint Plan of Care between hospice and the child's other medical providers in order to coordinate the curative treatments and hospice services.

Challenges of Concurrent Care

- Unclear boundaries between treatment and hospice providers.
- Unclear for parents.
- Understanding the role of hospice within the context of disease-modifying treatments.
- Delineating costs to hospice versus treatment.
- No uniformity in administration of concurrent care at state level.
- Complicated care coordination.
- Evolving plan of care.
- Working relationship with Medicaid Office.

Resources

Download the Toolkit 1.) Talking Points, 2.) Fact Sheet infographic and 3.) Open Letter to the Pediatric End Of Life Community. Explore this website for further state level documents on the implementation and background of concurrent care. Contact your state Medicaid director.

- Among the publicly available resources are state-level documents categorized on the Pediatric End-of-Life Care Research Group website <https://pedeolcare.utk.edu/>
- A graphical communication for Concurrent Care can be viewed or shared from this blog post <https://pedeolcare.utk.edu/introduction-to-concurrent-care/>
- Advocacy points from the mission statement about Concurrent Care research are available on the About page of the website <https://pedeolcare.utk.edu/about/>
- Preliminary Concurrent Care research findings are available in this [Infographic](#)
- Review this media guide for interviews with journalists [Media Guide for Scientists](#)
- Information which supports concurrent care issues <https://courageousparentsnetwork.org/parents/pediatric-palliative-care>
- Ongoing federal legislative efforts <https://www.chionline.org/chipacc-model/>
- Updates will be available ongoing from blog posts and social media
- Website blog posts: <https://pedeolcare.utk.edu/>
- Twitter <https://twitter.com/PedeolC>
- Facebook <https://www.facebook.com/pedeolcare>
- Hashtags: #pedpc #hapc #ACA #SCOTUS