

INSIGHT

How to Support Children and Youth with Special Health Care Needs and their Families as the COVID-19 Public Health Emergency Ends

Access to continuous health care coverage is a life-and-death issue for children and youth with special health care needs (CYSHCN). The unwinding of the COVID-19 public health emergency presents a challenge for many families whose children will now need to undergo a Medicaid eligibility redetermination. Family Voices, a national family-led organization of families and friends of CYSHCN and people with disabilities, partnered with Manatt Health to develop [three briefs](#) on key policy and operational recommendations to help minimize insurance coverage losses during the unwinding.

Cara Coleman, director of public policy and advocacy at Family Voices, shares her perspective on the challenges ahead and how to use the briefs to advocate for CYSHCN and their families.

What is one of the biggest challenges for families who are navigating the unwinding?

My biggest concern is the loss of coverage for CYSHCN who are eligible for Medicaid. This is compounded by the application and eligibility difficulties families encountered even prior to the pandemic. Many states are only issuing a one-time mailing to a last known address for communication about eligibility, and that is not sufficient. States need to proactively contact families about redetermination notices, and families should be given ample opportunity to provide updated address information.

Families also need plain language materials in multiple languages that explain how their access to care will change and what services and supports will no longer be covered by Medicaid. This information must be easily accessible for all families. I encourage everyone to learn [what your state is doing](#) to ensure families receive redetermination notices. We must remember that while the formal public health emergency may be ending, the ongoing crisis for many CYSHCN families is not.

READ THE BRIEF: [Strategies to Ensure Continuous Coverage for Children at the End of the COVID-19 Public Health Emergency](#) provides information on how states can support families.

How can the briefs help support CYSHCN and their families?

The public health emergency, its policies and flexibilities, and how it will affect each child and family is complex. The briefs do an excellent job of distilling critical health information into digestible facts and recommendations. I encourage everyone to:

- Create one-page tip sheets based on the briefs to share with families
- Use as guidance to assist families in navigating the unwinding
- Share the briefs with partners, Medicaid, and state agencies to create systems-level changes

READ THE BRIEF: Telehealth access is a great example of a service that will affect every family differently. [Maintaining Telehealth Access to Medicaid-Covered Pediatric Services After the End of the COVID-19 Public Health Emergency](#) is a helpful resource on this topic.

Who can partner to support families?

Partnership is critical to the successful unwinding of the public health emergency. Organizations like Family-to-Family Health Information Centers (F2Fs) have a direct line to families, understand the needs of families, and are excellent partners in designing family-friendly, health-literate communications and programs that meet those needs. F2Fs and advocates for CYSHCN and their families can bring the findings and recommendations from the briefs with them to meetings, forums, or partnership opportunities with Medicaid, Title V, and other state agencies in their respective state, territory, or tribal nation.

READ THE BRIEF: [Working With Community-Based Organizations and Individuals with Lived Experience to Support Continuity of Coverage at the End of the COVID-19 Public Health Emergency](#) has more information about how to partner effectively.