MAY 2023

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

This brief was updated in May 2023 to incorporate the new end date of the federal continuous coverage requirement.

Introduction

As a condition of receiving enhanced federal funds under the Families First Coronavirus Response Act, states are maintaining continuous enrollment of all Medicaid enrollees, and many states have also paused Children's Health Insurance Program (CHIP) renewals and disenrollments.[1,2,3] The continuous enrollment requirement ended on March 31, 2023, and many states have begun to process pending renewals. The unwinding of the federal continuous coverage enrollment (from this point forward referred to as "unwinding") requires states to redetermine Medicaid eligibility for more than 90 million beneficiaries, which will result in a high risk of eligible individuals losing Medicaid or CHIP coverage due to administrative or procedural reasons.[4,5]

[1] Manatt Health, State Strategies to Prepare for PHE Unwinding: Updating Addresses and Responding to Returned Mail.
[2] Families First Coronavirus Response Act, HR 6201, § 6008(b)(3).
[3] Centers for Medicare & Medicaid Services (CMS), Example of CHIP Disaster Relief State Plan Amendment.
[4] Manatt Health, New CMS Guidance on Expectations for Unwinding Federal Medicaid Continuous Coverage.
[5] CMS has issued guidance on its expectations for the PHE unwinding in an effort to minimize the number of Medicaid and CHIP members who lose coverage during the transition, including a State Health Officials (SHO) letter that clarifies CMS' expectations for state Medicaid and CHIP agencies as they prepare to process outstanding eligibility and enrollment actions when the federal continuous coverage requirements end. Key expectations include that states develop an unwinding operational plan and risk-based approach for prioritizing pending actions. See: CMS, SHO# 22-001 RE: Promoting Continuity of Coverage and Distributing Eligibility and Enrollment Workload in Medicaid, the Children's Health Insurance Program (CHIP), and Basic Health Program (BHP) Upon Conclusion of the COVID-19 Public Health Emergency.

Partnering with community-based organizations (CBOs), family-led organizations and individuals with lived experience to engage their communities is an effective strategy for states to communicate and assist people with managing the potential coverage impact at the end of the PHE.

Estimates suggest that 37.3 million children currently enrolled in Medicaid and CHIP are protected by the federal continuous coverage requirement and that 6.7 million children could lose Medicaid coverage and/or not successfully transition to the CHIP or Marketplace coverage for which they might be eligible.[6] Many families will have moved, and therefore they will not receive critical mailings from the Medicaid or CHIP agency—documents that lay out steps needed to maintain Medicaid/CHIP insurance or transition to Marketplace coverage. Due to administrative issues such as incorrect mailing addresses or lags in response times, it is possible that children eligible for Medicaid, CHIP or Marketplace coverage will become uninsured, creating a barrier to access to services that would be particularly problematic for children with special health care needs.[7]

CBOs and family-led organizations, such as Family-to-Family Health Information Centers (see box for more details), can help states ensure the efficacy of their unwinding plans and limit the number of children and families who lose coverage in this period while working to meet the expectations set by CMS to mitigate coverage loss.[8]

Family-to-Family (F2F) Health Information Centers

F2F Health Information Centers are one example of federally funded family-led organizations that could support state unwinding processes. The federal Maternal and Child Health Bureau funds an F2F in every state, D.C., five territories and three tribal nations. These family-led organizations are staffed by families of children/youth with special health care needs who have lived experience and/or expert knowledge of Medicaid and CHIP eligibility and enrollment processes. F2F Health Information Centers assist families with navigating systems of care, including Medicaid, CHIP and Marketplace coverage, and they support diverse families through their shared lived experience. These organizations also track important data related to the issues and concerns that families face when applying for or renewing Medicaid/CHIP and other public health benefits.

Find a F2F in your state here.

This issue brief, one of a three-part series focused on improving access to Medicaid, CHIP and Marketplace coverage for children at the end of the PHE, provides an overview of the following state strategies:

- Develop relationships with Medicaid enrollees, individuals with lived experience and family-led organizations that allow these critical stakeholders to provide ongoing feedback throughout the unwinding process (i.e., planning for unwinding, implementation, and post-unwinding);
- Partner with CBOs and family-led organizations to support real-time communication and feedback between the community and the state;

[6] Georgetown University Health Policy Institute: Center for Children and Families, Millions of Children May Lose Medicaid: What Can Be Done to Help Prevent Them From Becoming Uninsured?
[7] Georgetown University Health Policy Institute: Center for Children and Families, Millions of Children May Lose Medicaid: What Can Be Done to Help Prevent Them From Becoming Uninsured?
[8] Family Voices, Family to Family Health Information Centers.

- Engage CBOs and family-led organizations to provide direct support (e.g., explaining the importance of keeping contact information up-to-date or helping complete recertification forms) to Medicaid enrollees to maintain coverage through the unwinding process;
- Engage CBOs and family-led organizations to support bidirectional communication with racially, ethnically, linguistically and culturally diverse communities; and
- Encourage managed care organizations (MCOs)/managed care plans (MCPs) to closely coordinate with CBOs to enhance member outreach efforts.

Best Practices for Engaging CBOs and Individuals With Lived Experience in PHE Unwinding

States can leverage any or all of the best practices described in this brief to maximize the efficacy of their PHE unwinding plans and minimize the number of Medicaid/CHIP enrollees who lose coverage during the unwinding period. Across each of the recommendations below, states should ensure that community engagement initiatives elevate individuals with experience navigating Medicaid/CHIP who may be able to relate and build trusting relationships with the community more easily. Importantly, states should compensate CBOs and family-led organizations for their work, as these organizations are often under-resourced, and states should also ensure that all individuals with lived experience are compensated for their contributions.

- **Develop relationships with Medicaid enrollees, individuals with lived experience and family-led organizations that allow these critical stakeholders to provide ongoing feedback through existing channels throughout the unwinding process (i.e., planning for unwinding, implementation, and post-unwinding)**. States could leverage existing Medical Care Advisory Committees or similar entities to engage Medicaid enrollees to provide feedback on their experience during unwinding efforts. States could also establish an advisory group of individuals with lived experience (e.g., Medicaid enrollees, caregivers, families) specific to their unwinding efforts. This advisory group could be repurposed for other relevant community engagement when the PHE unwinding efforts conclude. To enhance efficacy, any commission should be led and staffed by individuals with lived experience or individuals with deep experience in the communities that they are tasked to engage. Note that States could engage these

State Financing Mechanisms to Compensate CBOs That Support Unwinding Efforts

States may consider the following funding streams to compensate CBOs and family-led organizations that they engage to support unwinding efforts:

- **American Rescue Plan Act (ARPA) or Other State Funds**: States could consider leveraging unallocated ARPA funding or other available funds to pay CBOs and F2Fs that support unwinding efforts. Massachusetts allocated $5 million from its ARPA funding to support a community-based outreach and education campaign.
- **Medicaid/CHIP Administrative Claiming and Federal Match**: States may leverage administrative funds to support unwinding efforts. Federal payment is available at a rate of 50% of state expenditures for expenses found necessary for proper administration of the State Plan.

committees and advisory groups as they plan for, implement, and conclude their unwinding efforts to ensure they are able to solicit and implement community feedback throughout the entirety of the unwinding process.

- **Partner with CBOs and family-led organizations to support real-time communication and feedback between the community and the state**. CBOs and family-led organizations that are engaged to support communication and to provide direct support to Medicaid enrollees during the unwinding period could also serve as a direct line of feedback to states to help them understand how they could better support their communities. States could charge CBOs and family-led organizations to develop a taskforce of community representatives and individuals with lived experience that gathers regularly to discuss the impact of the PHE unwinding on their children and families, and to strategize community-based and/or state-level solutions, which the CBOs and family-led organizations could report back to the state.[9] States may also consider meeting directly with the taskforce that the CBOs or family-led organizations organize. Note that states, CBOs and family-led organizations should make these meetings as "family-friendly" as possible by eliminating any barriers to participation. For example, meetings could be scheduled outside of typical work hours (i.e., early morning, late evening or weekends) and could include a virtual attendance option. States could also compensate participants for the cost of their participation, including the cost of transportation and/or childcare.[10]

  For example, Kids Win Missouri, a coalition of advocates for children, formed the Renewals and Ending the PHE Taskforce, comprising providers, CBOs and other advocates. The taskforce developed goals and questions for the state and planned to meet with Missouri Medicaid to help inform the state's unwinding efforts. The taskforce plans to continue to engage with the state throughout the unwinding process.[11]

  Alternatively, CBOs could assign an existing or new staff member to respond to questions and feedback from the community in real-time to ensure that time-sensitive issues are addressed promptly.

- **Engage CBOs and family-led organizations to provide direct support (e.g., explaining the importance of keeping contact information up-to-date or helping complete recertification forms) to Medicaid enrollees to maintain coverage through the unwinding process**. States may engage CBOs and family-led organizations to conduct outreach throughout their communities to offer support or respond to questions related to state requirements to maintain coverage. States could also fund CBOs and family-led organizations to establish a telephone helpline that community members or staff could call for support in completing their change-of-address form or to ask other questions related to their Medicaid coverage.

  For example, CBOs in Colorado are directly assisting Medicaid enrollees in updating their contact information.[12] Additionally, Massachusetts leveraged ARPA funding to support a community-based outreach and education campaign. This effort is led by Health Care for All and focuses on a three-pronged approach, which includes:

  – Leveraging established community and faith-based organizations to conduct outreach to individuals where they live and work;

[9] Community Catalyst, The Time is Now to Help Medicaid Enrollees Prepare for the End of the Public Health Emergency.
[10] Family Voices, Lucile Packard Foundation for Children's Health, Issue Brief: A Framework for Assessing Family Engagement in Systems Change.
[11] Community Catalyst, The Time is Now to Help Medicaid Enrollees Prepare for the End of the Public Health Emergency.
[12] National Academy for State Health Policy (NASHP), How States Are Getting Ready to Unwind Medicaid's Continuous Coverage Requirement.

  - Canvassing communities with the highest potential for coverage loss to conduct one-on-one outreach;
  - Launching a local media campaign across channels that reach diverse audiences.[13]

- **Engage CBOs to support communication with racially, ethnically, linguistically and culturally diverse communities**. States could partner or contract with CBOs and family-led organizations to communicate upcoming Medicaid policy changes to the communities they serve, ensuring that communities are aware of the implications of the end of the PHE and any actions that they must take in order to preserve their Medicaid coverage, such as updating their contact information and responding to requests for information from the Medicaid agency.[14] To do so, CBOs and family-led organizations could notify Medicaid beneficiaries of actionable steps that they must take to maintain coverage.

  In addition, states could partner or contract with CBOs and family-led organizations to review state and MCO messaging to ensure messages are effective. Such CBOs and family-led organizations could also engage their communities to review state, CBO and family-led organization messaging. For example, California developed a Coverage Ambassador program, through which the state has engaged a diverse set of organizations that will educate Medi-Cal beneficiaries on the steps necessary to maintain coverage.[15] The state released a Medi-Cal Continuous Coverage Requirement Communications Toolkit, which supplies tools for the ambassadors to leverage and clearly delineates their role and responsibilities.[16] California engaged its F2F Health Information Centers to provide feedback on its community-facing unwinding materials to ensure effectiveness within the community.

- **Encourage MCOs/MCPs to closely coordinate with CBOs and family-led organizations to enhance their member outreach efforts**. Some states may depend on MCOs to update members' contact information and communicate upcoming policy changes to their members (examples include Utah, Massachusetts and Colorado).[17] States could encourage MCOs to partner with CBOs and family-led organizations to support their efforts, leveraging the CBOs and family-led organizations typically stronger community ties to enhance member engagement.

Conclusion

Engaging CBOs, family-led organizations and individuals with lived experience is an effective strategy to minimize the number of children who will lose coverage during the unwinding. States may choose to leverage any or all of the approaches described above, as they could complement each other and become increasingly impactful together. The efficacy of the unwinding will depend in part on enrollee engagement, which CBOs and family-led organizations are uniquely positioned to support.

[13] Blue Cross Massachusetts Foundation, Massachusetts Medicaid Policy Institute, Manatt Health, The End of the Federal Continuous Coverage Requirement in MassHealth: Key Strategies for Reducing Coverage Loss.
[14] Georgetown University Health Policy Institute: Center for Children and Families, Unwinding the COVID Continuous Eligibility Requirement at the End of the Public Health Emergency: Tips for Advocates.
[15] California Department of Health Care Services (DHCS), Keeping Medi-Cal Beneficiaries Covered.
[16] DHCS, Medi-Cal Continuous Coverage Requirement Communications Toolkit.
[17] NASHP, How States Are Getting Ready to Unwind Medicaid's Continuous Coverage Requirement.

About Manatt Health

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About The Lucile Packard Foundation for Children's Health

Support for this work was provided by the Lucile Packard Foundation for Children's Health. The views presented here are those of the authors and do not reflect those of the Foundation or its staff. The Foundation's Program for Children with Special Health Care Needs invests in creating a more efficient and equitable system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families. Learn more at lpfch.org/CSHCN.