What should states consider when implementing H.R. 1?

Medicaid is a joint federal and state program that helps cover medical costs for people with limited income and vulnerable populations.[1] H.R.1, or the One Big Beautiful Bill Act (OBBA), is a reconciliation bill passed by Congress in mid-2025 that contained several important changes to Medicaid.[2]

Medicaid provides health and long-term care coverage to 83 million low-income children and adults in the United States. For patients with rare diseases, Medicaid is an essential, life-saving program that provides access to rare disease treatment, long-term care, and financial stability for families. As states develop policies and processes to implement the requirements of H.R. 1, the unique complexities facing the state's rare disease community should be accounted for.

Community Engagement Requirements Implementation Principles:

- Patients receiving home and community-based services should be automatically exempt from work requirements. In addition, states should avoid pausing, eliminating, or limiting Home and Community Based Services Waivers for patients with rare diseases and children.

- States must establish clear, public guidelines for caregivers of children under the age of 13 and people with disabilities. With accessible resources, many rare caregivers will qualify for exemptions or be able to count caregiving toward fulfilling work requirements.

- Account for the rare disease coding gap when designing ex parte verification processes. Approximately 97% of rare diseases have no specific ICD 10-CM Code.[3]

- Limiting the lookback period to one month and reverification of compliance to once per 12-month period to protect rare disease patients with episodic or progressive illnesses that may change month to month.

- Adopting all short-term hardship exemptions. For patients with rare conditions, short-term hardship events like in-patient hospital visits or travel out of state care are common work disruptions.

- Patients, their families, caregivers, and the advocacy organizations that support them should be represented in designing and testing the implementation of work requirements.

- Commit to enrollment verification every 6 months. Additional checks add administrative burden and unnecessary costs to states, leaving more room for error and paperwork for enrollees.

For patients with rare diseases, Medicaid is an essential, live-saving program. To learn more, visit our website or contact policy@rareadvocates.org

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[1] Medicaid (2025). Home. https://www.medicaid.gov/medicaid

[2] https://www.govtrack.us/congress/bills/119/hr1/text

[3] McMurry J, Matentzoglu N, Bailey K, Berg J, Jason C, Chute C, et al. Which rare diseases are best suited to diagnostic AI? A systematic selection framework. Zenodo; 2026. doi:10.5281/ZENODO.20520796