



Community Home Health & Telehealth Policies: Extend Flexibilities to Enable Critical Access Beyond the Public Health Emergency

Background

In the early weeks and months of the COVID-19 public health emergency, Congress and the Administration took important steps to ensure patients have access to essential care while the nation grappled with controlling the spread of the virus. Specific time-limited regulatory flexibilities have removed significant barriers to care and improved access for the 30 million Americans living with a rare disease or condition.

However, these flexibilities are at risk of going away when the public health emergency ends. We urge policymakers to recognize how these flexibilities have benefited members of the rare disease community and consider which policies should be kept in place after the public health emergency ends.

Rare Disease Community's Efforts to Date

- Temporary changes to CMS's home health policies have enabled rare disease patients to utilize essential but previously unavailable home health services during the pandemic.
 - For example, CMS has temporarily changed the definition of "homebound" to include individuals who have a condition that puts them at greater risk of COVID-19, making it possible for these patients to receive the Medicare home health benefit.
- In May, nearly 60 organizations joined a letter to HHS and CMS asking that the Administration consider the specific needs of rare disease patients as new guidelines and policies are issued.
- In response to CMS's interim final rule, the EveryLife Foundation asked CMS to ensure rare patients can continue to access in-home health care including injection and infusion services.
- Waiving restrictions to the provision of telehealth has enabled members of our community to access their providers remotely while mitigating the risk of infection during the COVID-19 crisis.
- In June, over 340 organizations wrote to Congress to request specific statutory changes to ensure patients continue to have access to telehealth services once the public health emergency ends.

Prioritizing Access to Home Health & Telehealth

- The rare disease community supports telehealth policies that would **remove the arbitrary restrictions on a patient's location, empower CMS to determine appropriate telehealth providers and services, extend the telehealth waiver authority to any public health emergency, and allow rural health clinics and community health centers to offer telehealth.**
- Congress and the Administration must act to ensure patients—especially those with a rare disease or other underlying condition—**continue to have access to home health and telehealth** even as the public health emergency and accompanying regulatory flexibilities eventually expire. Congress must act to ensure the flexibilities continue. Without action by Congress, service will be limited when the emergency declaration ends.

Rare Disease Legislative Advocates (RDIA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDIA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers.

Please contact Shannon von Felden (vonfelden@curetheprocess.org) to learn more about RDIA.