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MEDICAID HOME AND COMMUNITY-BASED WAIVERS

CMS Should Encourage States to Conduct Mortality Reviews for Individuals with Developmental Disabilities

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Highlights

Highlights of GAO-08-529, a report to the Ranking Member, Committee on Finance, U.S. Senate

Why GAO Did This Study

Deaths of individuals with developmental disabilities due to poor quality of care have been highlighted in the media. Prior GAO work has raised concerns about inadequate safeguards for such individuals receiving care through state Medicaid home and community-based services (HCBS) waivers. CMS approves and oversees these waivers. Safeguards include the review of, and follow-up action to, critical incidents—events that harm or have the potential to harm waiver beneficiaries. GAO was asked to examine the extent to which states (1) include, as a critical incident, deaths among individuals with developmental disabilities in waiver programs; (2) have basic components in place to review such deaths; and (3) have adopted additional components to review deaths. GAO interviewed state developmental disabilities agency officials and external stakeholders in 14 states, e-mailed a survey to 35 states and D.C., interviewed experts, and reviewed documents.

What GAO Recommends

GAO is making recommendations to CMS that include (1) encouraging states to conduct mortality reviews or broaden processes for such reviews and (2) establishing an expectation for reporting deaths to state protection and advocacy agencies. HHS stated that CMS concurred with the first recommendation. However, the agency did not fully address it. HHS did not state whether CMS agreed or disagreed with the second recommendation.

To view the full product, including the scope and methodology, click on GAO-08-529. For more information, contact John E. Dicken at (202) 512-7114 or dickenj@gao.gov.

What GAO Found

All 14 states whose officials GAO interviewed included death among individuals with developmental disabilities as a critical incident in their waiver programs. The developmental disabilities agencies in all 14 states required waiver service providers to report such deaths to the agencies. Consistent with CMS's expectation that states review critical incidents, nearly all states had processes in place to review these deaths. The extent to which states other than these 14 identified death as a critical incident has not been established.

All but 1 of the 14 states included most of the six basic mortality review components identified as important by experts when reviewing deaths among individuals with developmental disabilities, but states varied somewhat in how they implemented components. For example, some states reviewed unexpected deaths only, while other states reviewed all deaths of individuals receiving Medicaid HCBS services. Mortality reviews were typically conducted at a local level, such as a county or region. Review findings led to local actions, such as tailored training with individual providers, to address quality of care. Officials in 13 of the 14 states reported that they aggregated mortality data, for example, by cause of death and age, whereas nationwide, 37 of 50 states aggregated mortality data and 13 states did not. For example, one California region observed an increase in choking deaths among individuals with developmental disabilities in 2007 and increased its educational outreach to families about choking prevention. Officials in several states said they believed their mortality reviews had reduced the risk of death and led to improvements in the quality of their HCBS waiver services.

Four of the 14 states incorporated all additional components for more comprehensive mortality reviews. In general, these four additional components—state-level interdisciplinary mortality review committees, involvement of external stakeholders, statewide actions to address problems, and public reporting—gave the mortality reviews in these states greater accountability and transparency. Eleven of the 14 states had adopted at least one of these additional components. For example, 6 of the 14 states had interdisciplinary mortality review committees that reviewed deaths and that provided additional oversight to local review efforts, whereas nationwide, 24 of 50 states had review committees, and 26 states did not. In 6 of the 14 states, developmental disabilities agencies were not required to report deaths to the state protection and advocacy agencies, a key external stakeholder with authority to investigate deaths involving suspected abuse and neglect. Mortality reviews in 11 of the 14 states resulted in statewide actions, such as the issuance of safety alerts or new risk-prevention practices, to address quality-of-care concerns. Nationwide, 30 of 50 states took a statewide action to improve care, while 20 states did not. Four of the 14 states publicly reported mortality review information, such as posting annual mortality reports on their agency Web sites.