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COMING UP: HR 3995 ACTION ALERT

VOR Weekly E-Mail Update

July 25, 2008

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A closer look at tracking mortality in community settings

1. Summary: Deaths of developmentally disabled in home-care settings should get closer reviews: GAO

2. GAO RESULTS IN BRIEF

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1. Summary: Deaths of developmentally disabled in home-care settings should get closer reviews: GAO

Summary: Last week's VOR Weekly Update shared news of a new Government Accountability Office (GAO) report which considered mortality in home-care settings. GAO's July 09, 2008 indicated that states should more thoroughly investigate deaths of people with developmental disabilities who were receiving home- and community-based services for care. Specifically, GAO said that the the Centers for Medicare & Medicaid Services should pressure states to review such deaths more closely, the Government Accountability Office says. "Concerns about deaths resulting from poor quality of care and inadequate oversight of individuals with developmental disabilities

receiving community-based care," compelled Sen. Charles Grassley (R-IA) to request the report (GAO-08-529).

The 14 states included in the report are:

California,

Connecticut

Florida

Illinois

Iowa

Massachusetts

Minnesota

New York

Ohio

Oregon

Pennsylvania

Texas

Washington

Wisconsin

This news warranted additional coverage in VOR's Update. The full report can be found at www.gao.gov/new.items/d08529.pdf. The Results in Brief directly from the report follow.

2. GAO RESULTS IN BRIEF

MEDICAID HOME AND COMMUNITY-BASED WAIVERS: CMS Should Encourage States to Conduct Mortality Reviews for Individuals with Developmental Disabilities

GAO-08-529

May 2008

RESULTS IN BRIEF

All 14 states whose officials we interviewed included death among individuals with developmental disabilities as a critical incident in their Medicaid HCBS waiver programs and required that service providers report such deaths to developmental disabilities agencies. Consistent with CMS's expectations for critical incidents, developmental disability agencies in 13 of these 14 states had processes in place to review deaths among individuals with developmental disabilities. We do not know, however, whether states other than the 14 included such deaths as critical incidents and reviewed those deaths.

All but 1 of the 14 states whose officials we interviewed included most of the basic mortality review components identified as important by experts when reviewing deaths among individuals with developmental disabilities; however, states varied somewhat in how they implemented these components.

For example, some of the states reviewed only deaths involving suspected abuse or neglect and other unexpected deaths, such as those resulting from an undiagnosed condition, while other states reviewed all deaths of individuals receiving Medicaid HCBS waiver services. Eleven of the 14 states screened deaths using similar information, such as the circumstances surrounding a death, to identify cases for further review. In 11 of the 14 states, findings from mortality reviews conducted locally led to actions at that level to address quality of care, such as tailored training with individual providers. To identify trends in deaths among individuals with developmental disabilities, 13 of the 14 states reported that they aggregated mortality data, for instance, by the causes of death and age of beneficiary. Based on California's aggregation of mortality data, for example, an increase in 2007 in choking deaths was observed among individuals with developmental disabilities in one California region.

Further analysis revealed the increase was attributable to several choking deaths among individuals living in private family homes; as a result, the region increased its educational outreach to families about choking prevention.

Nationwide, 13 of 50 states did not aggregate mortality data. Officials in several states in which we conducted interviews said they believed that their mortality reviews had reduced the risk of death and led to improvements in the quality of HCBS waiver services. However, these states had not documented the impact of their reviews on mortality.

Four of the 14 states whose officials we interviewed—Connecticut, Massachusetts, Minnesota, and Ohio—incorporated all of the additional mortality review components, resulting in more comprehensive mortality reviews. Based on information provided by experts and state officials, we identified four additional components that include using state-level interdisciplinary mortality review committees, routinely involving external stakeholders, taking statewide actions based on mortality information to improve care, and publicly reporting mortality information. In general, these components gave the mortality reviews in these states greater accountability and transparency.

Eleven of the 14 states had adopted at least one of the four components. For example, 6 of the 14 states had interdisciplinary mortality review committees that examined in greater depth medically complex or unusual death cases and provided oversight to local review efforts.

Nationwide, 24 of 50 states reported having such a committee and 26 did not. Seven of the 14 states included in their review process stakeholders that were external to the developmental disabilities agency.

According to several state officials, the inclusion of external stakeholders promoted independence, which is important given the natural incentive for state agencies to minimize errors or program weaknesses. In 6 of the 14 states, state 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 in this

population. Protection and advocacy which helped to ensure transparency in the mortality review process, according to officials in one state developmental disabilities agency.

We are making three recommendations to the Administrator of CMS to help states address quality concerns and provide additional oversight of the care provided to individuals with developmental disabilities.

Specifically, we recommend that CMS -

(1) disseminate information to states about basic and additional components for mortality reviews;

(2) encourage states that do not include death as a critical incident or conduct mortality reviews to do both and encourage states that include death as a critical incident and conduct mortality reviews to broaden their review processes; and

(3) establish as an expectation for Medicaid HCBS waivers that states report all deaths among individuals with developmental disabilities receiving such services to their state office of protection and advocacy.

In commenting on a draft of this report, the Department of Health & Human Services (HHS) responded that CMS concurred with our first recommendation and will disseminate information about mortality reviews through its stakeholders, which include the National Association of State Medicaid Directors and the National Association of State Directors of Developmental Disabilities Services.

HHS also responded that CMS concurred with our second recommendation. However, the agency focused on suspicious deaths of individuals with developmental disabilities and did not respond to the part of our recommendation to encourage states that do not already do so to include death as a critical incident.

As noted in this report, screening mortality information about all deaths among individuals with developmental disabilities, not just suspicious deaths, is a basic component of a mortality review system and is necessary to determine whether further review of each death is warranted. HHS did not respond as to whether CMS agreed or disagreed with our third recommendation but recognized independent third-party reviews as important.

Agency officials in these 6 states told us that they relied on the media or concerned family members to alert them of deaths and that such notification was inconsistent and sometimes occurred long after the death. 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 based on mortality review information, while 20 did not. Four of the 14 states publicly reported mortality review information, which helped to ensure transparency in the mortality review process, according to officials in one state developmental disabilities agency.

Tamie Hopp

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