

May 2008

# MEDICAID HOME AND COMMUNITY- BASED WAIVERS

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





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](mailto:dickenj@gao.gov).

# MEDICAID HOME AND COMMUNITY-BASED WAIVERS

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

### 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.

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**Abbreviations**

CMS	Centers for Medicare & Medicaid Services
HCBS	home and community-based services
HHS	Department of Health & Human Services
ICF/MR	intermediate care facility for the mentally retarded

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United States Government Accountability Office  
Washington, DC 20548

May 23, 2008

The Honorable Charles E. Grassley  
Ranking Member  
Committee on Finance  
United States Senate

Dear Senator Grassley:

Medicaid, the joint federal-state health care financing program for qualifying low-income individuals, plays a major role in the financing of community-based long-term care for individuals with developmental disabilities, including those with mental retardation.<sup>1</sup> In 1981, Congress passed section 1915(c) of the Social Security Act, which allowed states to provide long-term care services, including personal care, day care, transportation, and home modification, through Medicaid home and community-based services (HCBS) waivers.<sup>2</sup> While individuals with developmental disabilities had often been cared for in large institutions, Medicaid waivers allowed them to receive services in residential settings such as small group homes or in the homes of parents or relatives.<sup>3</sup> The Centers for Medicare & Medicaid Services (CMS), the federal agency that manages Medicaid, is responsible for ensuring that states satisfactorily provide statutorily required assurances for HCBS waivers, which include having necessary safeguards to protect the health and welfare of waiver beneficiaries. To support this particular assurance, CMS requests states to specify which critical incidents—events that bring harm or have the potential to bring harm to waiver recipients—must be reported for review

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<sup>1</sup>Throughout this report we refer to individuals with mental retardation or who have other developmental disabilities as individuals with developmental disabilities.

<sup>2</sup>42 U.S.C. § 1396n(c)(2000).

<sup>3</sup>Prior to the waiver program, states had traditionally provided the majority of services for this population in institutional care settings such as intermediate care facilities for the mentally retarded (ICF/MR). In 2006, the majority of individuals with developmental disabilities served by Medicaid waivers—excluding those living in private homes with relatives—lived in residential settings, such as group homes, with six or fewer residents. However, ICF/MRs still play a significant role in providing long-term care services to persons with developmental disabilities, especially those with the greatest care needs who may not be able to live in the community. In 2004, about 100,000 individuals received care in ICF/MRs.

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and follow-up action. CMS identifies death as an example of a critical incident, but does not specify how states should review deaths.

Our 2003 report raised concerns about the need for CMS to provide states with more detailed criteria regarding the necessary components of an HCBS waiver quality assurance system, and about the limited information provided by states to CMS on their mechanisms to monitor the quality of care provided to waiver beneficiaries.<sup>4</sup> Since 2004, several local and national newspapers have reported on deaths that resulted from poor quality of care among individuals with developmental disabilities living in group homes. Individuals with developmental disabilities are vulnerable because of their cognitive and physical impairments and dependency on caregivers for assistance with many activities of daily living, such as eating and bathing. For example, a 63-year-old man with visual impairment, arthritis, and significant cognitive disabilities was living in a group home that provided supportive care in the community and also offered recreational activities. According to his legal guardians, they were notified in 2004 that he had suffered a fatal heart attack. In part because he did not have a history of heart problems, his guardians requested an autopsy. The autopsy report identified quality-of-care concerns: the individual choked to death on what appeared to be part of a sandwich, even though he was supposed to be fed pureed food. A subsequent investigation of the death and conditions in the group home found that the home was understaffed and that staff did not consistently prepare meals to meet the special needs of residents.

In light of concerns about deaths resulting from poor quality of care and inadequate oversight of individuals with developmental disabilities receiving community-based care, you asked us to review states' current processes for conducting mortality reviews and states' use of mortality information to address quality-of-care concerns in Medicaid's HCBS waiver program. Specifically, we examined the extent to which (1) states include death among individuals with developmental disabilities as a critical incident in waiver programs, (2) states have some basic components in place to review deaths of individuals with developmental disabilities in waiver programs, and (3) states have incorporated any additional components to review deaths of individuals with developmental disabilities in waiver programs.

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<sup>4</sup>GAO, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened*, [GAO-03-576](#) (Washington, D.C.: June 20, 2003).

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To assess whether states include death among individuals with developmental disabilities as a critical incident in waiver programs, we conducted interviews with state developmental disabilities agency officials in 14 states.<sup>5</sup> To identify the basic components of a mortality review process, we conducted a literature review, interviewed experts in the field of developmental disabilities, and reviewed documents authored by these experts. These experts and state developmental disabilities agency officials who conduct mortality reviews also contributed to the identification of additional components of more comprehensive mortality review processes. There may be other components for mortality reviews that were not brought to our attention. To determine the extent to which states incorporate both these basic and additional components into mortality reviews, we conducted interviews with state developmental disabilities agency officials in the 14 states and reviewed documents related to their mortality review processes.<sup>6</sup> We visited 4 of the 14 states (Connecticut, Ohio, Oregon, and Texas) to gather detailed information about how states review deaths of individuals with developmental disabilities. We selected these four states because, among other characteristics, they had well-established mortality review processes or a large number of individuals with developmental disabilities being served through a Medicaid HCBS waiver. We conducted focused telephone interviews with the other 10 of 14 states that served the largest number of individuals with developmental disabilities through Medicaid HCBS waivers. Combined, these 14 states served approximately two-thirds of Medicaid waiver beneficiaries with developmental disabilities nationally in 2005. However, the mortality review processes of this sample of 14 states cannot be generalized to all states nationwide. We conducted a brief e-mail survey of state developmental disabilities officials in the other 35 states and the District of Columbia requesting information on three broad aspects of mortality review processes.<sup>7</sup> We also conducted interviews with state protection and advocacy agencies in the 14 states and the District of

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<sup>5</sup>These states are California, Connecticut, Florida, Iowa, Illinois, Massachusetts, Minnesota, New York, Ohio, Oregon, Pennsylvania, Texas, Washington, and Wisconsin.

<sup>6</sup>We limited our review to adults (as defined by each state) with developmental disabilities receiving Medicaid HCBS waiver services.

<sup>7</sup>We collected information from 49 states and the District of Columbia. Throughout this report, we refer to the District of Columbia as a state. We excluded Arizona because it supported services for the developmentally disabled through a demonstration project waiver under section 1115 of the Social Security Act rather than a home and community-based services waiver under section 1915(c).

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Columbia.<sup>8</sup> Although we did not evaluate the effectiveness of state mortality review processes, the data we collected allowed us to make comparisons across states and to identify states with more comprehensive mortality review processes. We conducted our review from December 2006 through April 2008 in accordance with generally accepted government auditing standards. (For a more detailed description of our scope and methodology, see app. I.)

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## 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

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<sup>8</sup>The role of a protection and advocacy agency is to protect the legal and human rights of people with developmental disabilities. Although the District of Columbia was not in our sample of 14 states, we contacted this protection and advocacy agency because of local media reports about deaths resulting from alleged abuse or neglect among individuals with developmental disabilities.

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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 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,

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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.

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## Background

In 2004, Medicaid HCBS waiver expenditures totaled \$20.5 billion, with about 74 percent (\$15.2 billion) devoted to supporting community-based care for individuals with developmental disabilities. About 40 percent (415,053) of individuals served through such waivers had developmental disabilities.<sup>9</sup> Expenditures per person on this population are higher than

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<sup>9</sup>States can target their developmental disability waiver programs specifically to individuals with mental retardation or to persons with any type of developmental disability.

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for other groups served through the waivers, such as the elderly, because developmentally disabled individuals often require supportive care on a 24-hour basis. In 2004, annual Medicaid HCBS waiver expenditures per person served were \$36,697 on average for individuals with developmental disabilities compared with \$6,266 on average for elderly individuals.<sup>10</sup> Fifty states had 1915(c) waiver programs for individuals with developmental disabilities in 2006.<sup>11</sup> Waiver services vary by state but include services intended to help individuals live as independently as possible in the community.

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## Eligibility

To be eligible for Medicaid HCBS waiver services, including services for individuals with developmental disabilities, individuals must meet the state's criteria for needing the level of care provided in an institution, such as an ICF/MR, and be able to receive care in the community at a cost generally not exceeding the cost of institutional care.<sup>12</sup> As described in CMS's guidance for HCBS waivers, a developmental disability is defined as a severe, chronic disability, attributable to mental or physical impairments, with onset before age 22. Individuals with developmental disabilities are limited in their ability to carry out several major life activities, including self-care and mobility.

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## Waiver Quality

To receive federal funds for Medicaid HCBS waiver services, states must satisfactorily provide the statutory assurances for the 1915(c) waiver program that include having necessary safeguards to protect the health and welfare of beneficiaries.<sup>13</sup> CMS requires that states submit waiver applications that identify and describe how they will provide each of the statutory assurances. On the waiver application, CMS expects as part of the health and welfare assurance that states specify (1) which critical incidents states require to be reported to developmental disabilities agencies and appropriate authorities for review and (2) the follow-up

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<sup>10</sup>The Kaiser Commission on Medicaid and the Uninsured, *Medicaid Home and Community-Based Service Programs: Data Update* (Washington, D.C.: December 2007), <http://www.kff.org/medicaid/7720.cfm> (accessed May 6, 2008).

<sup>11</sup>Arizona did not operate a 1915(c) waiver for individuals with developmental disabilities (see footnote 7).

<sup>12</sup>The average cost of community care under a waiver cannot exceed the average cost of care in an institution.

<sup>13</sup>Other assurances include determining level of care needs and financial accountability.

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actions required if the state identifies a situation in which a beneficiary was not being safeguarded.<sup>14</sup> CMS guidance for waiver applications instructs that incidents of abuse, neglect, and exploitation, at a minimum, be reported and reviewed; states may define other events as critical, as well.<sup>15</sup> For example, CMS identifies death as an event that states may include as a critical incident.<sup>16</sup>

When reviewing HCBS waiver applications, CMS determines whether states meet program expectations, such as including the entity responsible for managing critical incidents to demonstrate necessary safeguards are in place. Initial waiver applications, if approved, are approved for a 3-year period, and subsequent applications are approved for an additional 5-year period, unless CMS determines that the assurances provided during the preceding term have not been met.<sup>17</sup> In a 2003 report, we examined the adequacy of CMS's oversight of state Medicaid waiver programs and recommended that the Administrator of CMS develop and provide states with more detailed criteria regarding the necessary components of an HCBS waiver quality assurance system.<sup>18</sup>

In response to our recommendation, CMS added an expectation to its Medicaid HCBS waiver program for states to improve the quality of waiver services and has implemented this new expectation in the form of an additional section on the HCBS waiver application. CMS defines quality improvement as the process of collecting information about Medicaid HCBS waiver programs to identify and correct concerns and to identify areas for improving the care provided to waiver beneficiaries. States can use information gathered from their critical incident reviews to determine whether strategies are needed to improve the quality of care. States applying for new waivers or waiver renewals after May 2005 were asked to

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<sup>14</sup>For each assurance required under section 1915(c) waivers, CMS has identified expectations for how states will provide these assurances, including expectations for the types of evidence that states submit on their applications to demonstrate the assurances are met.

<sup>15</sup>State definitions of critical incidents are generally specified in state-specific statutes or regulations.

<sup>16</sup>A serious injury that requires medical intervention or results in hospitalization is another example of an event that states may include in their definition of a critical incident.

<sup>17</sup>See 42 U.S.C. § 1396n(c)(3).

<sup>18</sup>[GAO-03-576](#).

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submit a detailed description of their quality improvement strategies.<sup>19</sup> For example, CMS guidance directs states to describe processes used to measure the performance of their waiver programs and to develop initiatives for quality improvement. CMS is encouraging and helping states to develop quality improvement strategies. As of October 2007, CMS had provided technical assistance to more than 40 states and more than 140 waiver programs that requested assistance in developing and implementing their quality improvement strategies for the Medicaid HCBS waiver programs. In addition, a provision of the Deficit Reduction Act of 2005 requires the Agency for Healthcare Research and Quality to develop HCBS quality-of-care measures, which CMS may incorporate into its waiver program if the measures reinforce the agency's expectations for states regarding quality improvement.<sup>20</sup>

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## State Operation of Waiver Programs

When a state receives a Medicaid HCBS waiver, the state's Medicaid agency is accountable to CMS for compliance with waiver program expectations. State Medicaid agencies may delegate administrative and operational responsibility for waiver programs to the department or agency with jurisdiction over the specific population served or services provided. For waivers serving individuals with developmental disabilities, operational responsibility is often delegated to the state developmental disabilities agency. State developmental disabilities agencies may then contract with local providers, networks, or agencies to provide or arrange for beneficiary services. Some states use state employees to provide waiver services to individuals with developmental disabilities, such as case management services that include individual assessments and monitoring of care.

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## Protection and Advocacy Agencies

State protection and advocacy agencies may be involved with state developmental disabilities agencies in the review of critical incidents among individuals with developmental disabilities where there is suspicion of abuse or neglect. The Developmental Disabilities Assistance and Bill of Rights Act of 1975 established the protection and advocacy

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<sup>19</sup>CMS officials told us that multiple states initially resisted providing information about their quality improvement strategies on the waiver application. For one of these states, CMS requested quarterly reports about the state's quality improvement strategy as a condition of approval.

<sup>20</sup>Pub. L. No. 109-171, §6086(b), 120 Stat. 4, 127 (2006).

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system to protect the legal and human rights of people with developmental disabilities.<sup>21</sup> In order to receive federal protection and advocacy funding, states must have a protection and advocacy agency, independent of any service provider.<sup>22</sup>

Given that abuse and neglect among individuals with developmental disabilities might not always be evident, protection and advocacy agencies play an important role in monitoring services provided to such individuals. The Developmental Disabilities Assistance and Bill of Rights Act, as amended, authorizes funding for protection and advocacy agencies to (1) investigate allegations of abuse or neglect when reported; (2) investigate suspected abuse or neglect when there is probable cause that incidents occurred; (3) pursue legal, administrative, and other appropriate remedies on behalf of individuals with developmental disabilities; and (4) provide information on developmental disability programs to the public, among other things. As a condition of funding, the act requires protection and advocacy agencies to have access to individuals with developmental disabilities and to their records, including reports prepared by agencies or staff on injuries or deaths. The act also requires, as a condition of funding, that states provide information—to the extent it is available—on the adequacy of HCBS waiver services to their protection and advocacy agencies.

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## All States Whose Officials We Interviewed Include Death as a Critical Incident

All 14 states whose officials we interviewed included death among individuals with developmental disabilities as a critical incident in their waiver programs. Officials in these states told us that the developmental disabilities agency required waiver services providers to report to the agency deaths of individuals with developmental disabilities. Consistent with CMS's expectation that states review critical incidents, the developmental disabilities agencies in 13 of the 14 states we interviewed had processes in place to review deaths. We do not know if states other than these 14 define, report, and review deaths as critical incidents. Because most states have laws that require reporting to coroners or medical examiners when the cause of a death is unknown or unnatural, it is likely that at least some deaths of individuals with developmental

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<sup>21</sup>Pub. L. No. 94-103, 89 Stat. 486 (codified, as amended, at 42 U.S.C. § 15043).

<sup>22</sup>Most protection and advocacy agencies are private nonprofit organizations.

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disabilities in the remaining 36 states are investigated.<sup>23</sup> However, we did not review the extent to which information about such investigations is shared with the developmental disabilities agencies.

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## Six Basic Mortality Review Components Identified as Important by Experts Are Used by Most States Whose Officials We Interviewed

All but 1 of the 14 states whose officials we interviewed included most of the six basic mortality review components experts identified as important when reviewing deaths among individuals with developmental disabilities; however, states varied somewhat in how they implemented these components. For example, some states' officials said they reviewed unexpected deaths only, whereas others reviewed deaths of all developmentally disabled individuals receiving state-funded services. Screening and reviews in most states were typically conducted at a local level, such as a county or region, and review findings led to local actions, such as tailored training with individual providers, to address quality of care. Officials in most of the 14 states in which we conducted interviews reported that they aggregated mortality information. Officials in several of the 14 states in which we conducted interviews told us they believed mortality reviews reduced the risk of death and improved the quality of services provided; however, these states had not documented the impact of reviews on mortality.

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## Six Basic Components Identified as Important for Mortality Reviews

We identified and defined six basic components for state mortality reviews, based on interviews with five developmental disabilities experts and documents they authored (see table 1). The five experts believed that these components were important when reviewing deaths among individuals with developmental disabilities. Our literature review added support to the identification of these components for mortality reviews. First, standard information is collected about the individual's death, and this information is screened by developmental disabilities agency staff to determine if further review of the death is needed (component 1). If it is determined that a mortality review is warranted—for example, if the death was unexpected or the screening suggests a possible quality-of-care concern—officials may conduct a more in-depth review to evaluate the cause and circumstances of the death and the individual's medical condition (component 2). Mortality reviews include medical professionals (component 3). The mortality review process is documented

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<sup>23</sup>Some states also specifically require the reporting of any deaths resulting from abuse or neglect.

(component 4) and may result in recommendations that address any quality-of-care concerns identified (component 5). Mortality data for deaths among individuals with developmental disabilities are aggregated to identify trends over time (component 6). For example, aggregated data can indicate patterns by cause of death, age, services received, or other programmatic factors.

**Table 1: Description of Six Basic Components of Developmental Disabilities Agency Mortality Reviews for Individuals with Developmental Disabilities**

<b>Component</b>	<b>Description</b>
1. Screen individual deaths with standard information	<ul style="list-style-type: none"> <li>• A preliminary screen of standard mortality information is conducted to determine whether a death requires further review or investigation.</li> <li>• The same information is routinely collected for each death.</li> </ul>
2. Review unexpected deaths, at a minimum	<ul style="list-style-type: none"> <li>• Cause and circumstances of deaths are reviewed to identify issues or concerns that may have compromised the overall care provided.</li> <li>• Unexpected deaths may include those that resulted from an undiagnosed condition, were accidental, or were suspicious for possible abuse or neglect.</li> </ul>
3. Routinely include medical professionals in mortality reviews	<ul style="list-style-type: none"> <li>• Medical professionals, including registered nurses or physicians, should participate in mortality reviews because individuals with developmental disabilities often have complex medical characteristics.</li> </ul>
4. Document mortality review process, findings, or recommendations	<ul style="list-style-type: none"> <li>• Records of the mortality review process are maintained and may include meeting minutes or summary reports.</li> </ul>
5. Use mortality information to address quality of care	<ul style="list-style-type: none"> <li>• Information resulting from the mortality review process should be used to improve the quality of care provided.</li> <li>• If mortality review findings apply to statewide practices, state agencies make the necessary changes to their policies.</li> </ul>
6. Aggregate mortality data over time to identify trends	<ul style="list-style-type: none"> <li>• Data about deaths among individuals with developmental disabilities, such as cause of death and demographic information, are aggregated over time to identify patterns and trends.</li> </ul>

Source: GAO analysis.

Note: To develop this table, GAO analyzed information provided by experts in the field of developmental disabilities and performed a literature review.

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Figure 1 illustrates how a state incorporated the six components in an actual mortality review involving a 44-year-old woman with developmental disabilities. The woman died of pancreatitis while living in a community group home and receiving Medicaid HCBS waiver services.<sup>24</sup>

**Figure 1: Example of State Mortality Review Processes**

Upon screening mortality information (**component 1**), local developmental disabilities officials determined that a 44-year-old woman's death from pancreatitis was unexpected and that she also had fallen and sustained a head injury, which resulted in a hospitalization prior to her death. Therefore, the case was identified as one warranting a more in-depth mortality review (**component 2**).

Medical professionals within the developmental disabilities agency reviewed the case (**component 3**) and found no indications that the woman was experiencing any health problems in the month preceding her death. The woman had been taking a medication for behavior management (Valproic acid). One possible adverse reaction associated with Valproic acid use is pancreatitis. Reviewers determined the fall and subsequent head injury to be an accident, but the deceased's blood levels indicated that she had an undiagnosed case of pancreatitis in its advanced stages.

The review of the case and recommendations made based on review findings were documented by the developmental disabilities agency (**component 4**).

As a result of this case, the agency nurses now track individuals who take Valproic acid and discuss at quarterly meetings how these individuals are being monitored (**component 5**).

The developmental disabilities agency included this case in its aggregation of 2006 mortality data by cause. For example, this death was counted as an unexpected death because it was not related to a known medical condition (**component 6**).

Source: GAO review of documents provided by one state developmental disabilities agency.

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## Thirteen of 14 States Incorporate Most of the Basic Mortality Review Components, but Some Variation Exists

All but 1 of the 14 states whose officials we interviewed included most of the basic mortality review components identified by experts as important when reviewing deaths, but some variation existed (see table 2). The one state that did not include most of these components was Texas. While developmental disabilities agency officials in Texas told us that state-level officials screened some standard information about deaths, they said the agency did not have a systematic process for reviewing deaths to identify and address quality-of-care issues. Instead, information was referred to investigative authorities, such as adult protective services, if the screening

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<sup>24</sup>Pancreatitis is an acute or chronic inflammation of the pancreas, the organ that produces hormones to help regulate blood sugar levels, metabolism, and digestion. Pancreatitis may be caused by certain medications.

process revealed the death was suspicious. Texas state officials also told us that they did not currently aggregate mortality data.

**Table 2: Use of the Six Basic Components for Mortality Reviews by 14 States, as of December 2007**

Component	States													
	Calif.	Conn.	Fla.	Ill.	Iowa	Mass.	Minn.	N.Y.	Ohio	Ore.	Pa.	Tex.	Wash.	Wisc.
Screen individual deaths with standard information	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Review unexpected deaths, at a minimum	●	●	●	⊗ <sup>a</sup>	●	●	●	●	●	●	●	⊗	●	●
Routinely include medical professionals in mortality reviews	●	●	●	●	⊗ <sup>b</sup>	●	●	●	●	●	●	⊗	●	⊗ <sup>b</sup>
Document mortality review process, findings, or recommendations	●	●	●	●	●	●	●	●	●	●	●	⊗	●	●
Use mortality review information to address quality of care	●	●	●	●	●	●	●	●	●	●	●	⊗	●	●
Aggregate mortality data over time to identify trends	●	●	●	●	●	●	●	●	●	●	●	⊗	●	●

Source: GAO interviews with state developmental disabilities agency officials.

Legend

- = Implemented this component all the time
- ⊗ = Did not implement this component

Note: These 14 states served approximately two-thirds of Medicaid waiver beneficiaries with developmental disabilities nationally in 2005.

<sup>a</sup>Developmental disabilities agency staff might review certain deaths among individuals with developmental disabilities that were unexpected.

<sup>b</sup>Medical professionals were only included on an as-needed basis.

However, there was variation among the states in how they implemented the six components. Officials in some states in which we conducted interviews told us they reviewed only deaths determined to be unexpected or suspicious, but in other states all deaths among individuals receiving agency services were reviewed. Some states also used criteria other than the cause of death to determine whether a case warranted further review. In Washington, for example, all suspicious deaths in community settings were reviewed regardless of cause of death, but unanticipated deaths were reviewed on a case-by-case basis, depending on the outcome of a local-level screening process. In Massachusetts, officials routinely reviewed the deaths of all individuals, including those residing in a private home, if they

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had been receiving more than 15 hours of agency-funded community support services. Agency officials in other states we interviewed also told us that they did not generally have enough information to conduct a thorough mortality review for individuals receiving limited waiver services. Moreover, the extent to which states used mortality review information to address quality of care varied. For example, while officials in 13 of 14 states told us they used information from individual cases to take actions on the basis of mortality review findings (e.g., to enhance provider training), officials in 3 of 14 states reported conducting further research on issues identified during mortality reviews.

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### Screening Similar Mortality Information and Reviewing Unexpected Deaths Occurs Locally in Most States Whose Officials We Interviewed

In 11 of the 14 states whose officials we interviewed, the screening of similar mortality information, such as the circumstances surrounding a death, was conducted by county-level or regional developmental disabilities agency officials, and the results were used to identify cases for further review. Similarly, in most of these states local developmental disabilities officials undertook a more in-depth mortality review of those cases identified during the screening process as unexpected or suspicious for abuse or neglect, or those in which a possible quality-of-care concern was identified.

### Similar Mortality Information Usually Screened Locally

According to developmental disabilities officials in 11 of the 14 states in which we conducted interviews, similar mortality information, such as the cause of death, was routinely screened at a local level. Local officials collected and used this information to identify suspicious or unexpected deaths, often as part of states' critical incident management systems. Specifically, local officials screened mortality information such as the cause of death, the circumstances surrounding a death (e.g., whether the death was an accident or witnessed by a direct care provider), and the individual's diagnoses or clinical conditions prior to death. Screening this information allows local agency officials to identify cases of possible abuse or neglect of Medicaid HCBS waiver beneficiaries and respond to such cases by providing for the safety of other individuals with developmental disabilities cared for in the same setting, as well as referring the cases to the appropriate authorities for criminal investigations. In Florida, for example, local nurses, who were developmental disabilities agency officials, screened information about the circumstances surrounding deaths to determine if they warranted further review. When the local nurses suspected abuse or neglect, adult protective services and law enforcement officials were notified to conduct an investigation. State developmental disabilities officials in a few of the 14 states told us that they also used the screening process to determine if

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## Mortality Reviews Mostly Conducted Locally

further review should be conducted for expected deaths or for cases not considered suspicious but where possible quality-of-care concerns existed.

Based on the results of the screening process, reviews of deaths among individuals with developmental disabilities also occurred at the local level in 11 of 14 states. These 11 states conducted reviews locally because the developmental disabilities agency oversight for waiver services was delegated to counties or regions.<sup>25</sup> In addition to reviewing in greater depth the cause and circumstances surrounding the death and the individual's clinical diagnoses and health conditions, officials in most of the 14 states told us that they also reviewed hospital records and health care professionals' progress notes, as well as autopsy findings when available. Lab reports and individual support or behavioral plans might also be reviewed to better understand each case. Reviewing multiple pieces of information surrounding the death is useful because they can show whether appropriate medical care was provided in the days and months before death and whether individual support plans were followed. For example, the mortality review process could reveal that an individual choked to death on solid food but that the individual's support plan indicated he or she was supposed to receive a pureed diet. Similarly, a review of the medical records of an individual who died from influenza or pneumonia could show whether he or she had received vaccines for these conditions.

Mortality reviews also were used to determine whether quality-of-care issues unrelated to the death existed. For example, officials in Ohio told us that in reviewing one death, the documentation in the individual support plan outlining the care that was supposed to be delivered did not match the care that had actually been provided. While the mortality review determined that the care the person received did not contribute to the death, concerns were raised that direct care staff was not following the individual's support plan.

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<sup>25</sup>An advantage of developmental disabilities agency case workers and nurses conducting mortality reviews locally is that they are more familiar with the provision and monitoring of beneficiaries' care than officials at the state level.

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## Many Actions to Address Quality of Care Taken Locally, While Mortality Information Is Aggregated Statewide in 13 of 14 States

While developmental disabilities agency officials in the 14 states aggregated mortality information statewide, they told us that local-level officials use mortality review information to take local actions to address quality-of-care concerns. Based on mortality review findings, nearly all 14 states had provided tailored training or technical assistance to direct care providers in a particular county or region. For example, when officials in Washington identified an increase in drowning among individuals with seizure disorders in a particular region, the developmental disabilities agency retrained its providers in that region to try to prevent future occurrences. In addition, based on their mortality reviews, officials in Pennsylvania told us they provided targeted training on choking to a local provider because of a trend in choking deaths among individuals with developmental disabilities served by that provider. Officials we interviewed in other states also cited targeted training or assistance to local providers.

As shown in table 2, 13 of the 14 states aggregated mortality data. These states aggregated data by variables including age, cause of death, the type of program or services provided to individuals with developmental disabilities, or other programmatic factors to identify trends over time. Officials in these states told us that aggregating mortality data was useful because it allowed them to identify trends, such as determining if particular types of deaths are isolated or part of a pattern. For example, in March 2007, officials from California's developmental disabilities agency observed an increased mortality rate among individuals with developmental disabilities in one region, and further analysis revealed the increase was attributable to several choking deaths among individuals living in private family homes. This region increased its educational outreach to families on the topic of choking prevention. In addition to aggregating mortality data, Connecticut, Massachusetts, and California calculated mortality rates among individuals with developmental disabilities. Connecticut and Massachusetts officials used aggregated mortality data to make broad comparisons with each other as well as with mortality rates for the general population in their states and across the nation. Officials in Massachusetts also calculated cause-specific mortality rates for individuals with developmental disabilities; they recently found that breast-cancer mortality rates were higher over a 5-year period for Massachusetts's women with developmental disabilities than for the general state population and nationwide.

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All but 1 of the 14 states in which we conducted interviews reported aggregating mortality data, and 24 of the 36 states that completed our e-mail survey reported doing so. Combined, 13 of 50 states did not aggregate mortality data, and 37 did. Among these 37 states, more than 80 percent aggregated mortality data on variables that included the cause of death, age, and other factors, such as the county or region where the death occurred, diagnosis at time of death, and whether an autopsy was performed or a medical examiner was involved in the case. In addition, nearly two-thirds of the 37 states nationwide that aggregated mortality data also aggregated on the variable of program type or type of services provided to the individual with developmental disabilities prior to his or her death. Thirteen states nationwide reported they did not aggregate mortality data for these individuals at the time we did our work.

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### Officials in Several States in Which We Conducted Interviews Believed Mortality Reviews Reduce Risk of Death and Improve Quality of Care

Officials in several states in which we conducted interviews said they believed that their mortality review processes had reduced the risk of death and served as one means for improving the quality of services provided in their HCBS waiver programs. However, these states had not documented the impact of reviews on mortality. Officials in some states also said that the reviews had contributed to a decrease in critical incidents, which might have resulted in reduced mortality. For example, a Connecticut state official told us that the implementation of mortality review recommendations, such as improving the competency of direct care staff in managing swallowing risks, had likely reduced the number of critical incidents among individuals with developmental disabilities. In addition, developmental disabilities agency officials in Oregon told us that they believed mortality review findings and subsequent actions, such as enhancing providers' procedures for handling critical incidents that can result in death, had led to quality-of-care improvements for this population. Officials in 11 of the 14 states we interviewed told us that they considered their mortality review processes for deaths among individuals with developmental disabilities to be one aspect of their waiver's overall quality improvement strategy.

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## A Few of the 14 States Incorporate Additional Components, Resulting in More Comprehensive Mortality Reviews

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. We identified and defined four additional components based on information provided by experts and state officials. In general, these additional components—using state-level interdisciplinary mortality review committees, involvement of external stakeholders, taking statewide actions based on mortality information to improve care, 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 the additional components. For example, 6 of the 14 states had interdisciplinary mortality review committees that provided additional oversight and added value to local mortality review efforts. Seven of the 14 states routinely included stakeholders external to the developmental disabilities agency in their mortality reviews, and several state officials told us that stakeholder involvement promoted independence or shared accountability.

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## Additional Mortality Review Components Provide Greater Accountability and Transparency

Four of the 14 states whose officials we interviewed incorporated all four additional mortality review components that we identified and defined for more comprehensive review processes. The additional components were identified based on interviews with five developmental disabilities experts and state officials.<sup>26</sup> Another 7 of the 14 states incorporated one or two additional components (Florida, Illinois, New York, Oregon, Pennsylvania, Washington, and Wisconsin). Eleven of the 14 states had adopted at least one of the additional components. The inclusion of these four components—using a state-level interdisciplinary mortality review committee, including external stakeholders in the review process, taking statewide actions based on mortality information to improve care, and publicly reporting mortality information—generally gave the mortality review processes in these states greater accountability and transparency (see table 3). State-level committees include professionals with various experiences in the field of developmental disabilities who review selected deaths to assess factors that may have contributed to death, such as medical or supportive care. Having a representative of the state’s protection and advocacy agency sit on the state-level mortality review committee is one example of how a developmental disabilities agency may

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<sup>26</sup>Similar to the basic components, additional components were identified based on a review of documents authored by these experts and a literature review.

routinely involve stakeholders not directly associated with the agency in its review process. When significant quality-of-care concerns are identified by mortality reviews, the state developmental disabilities agency uses such information to take statewide actions, such as requiring specific training for providers' direct care staff statewide in order to improve care for all waiver beneficiaries. The developmental disabilities agency publicly reports mortality information, such as posting on its Web site aggregated data about the number and causes of deaths among individuals who received care by the agency.

**Table 3: Description of Four Additional Components of Developmental Disabilities Agency Mortality Reviews for Individuals with Developmental Disabilities**

Component	Description
Use a state-level interdisciplinary mortality review committee (e.g., overseen by developmental disabilities agency)	<ul style="list-style-type: none"> <li>• Committees consist of professionals with experience in the field of developmental disabilities from various disciplines. They routinely review and discuss individual deaths to identify quality-of-care concerns.</li> <li>• Committees can provide a comprehensive review of deaths of individuals with developmental disabilities, who often have complex medical and social needs.</li> </ul>
Routinely include external stakeholders in review process (e.g., protection and advocacy agency)	<ul style="list-style-type: none"> <li>• Individual stakeholders, who are not directly associated with the developmental disabilities agency that provides or arranges for the provision of care, are included in the agency's mortality review process.</li> <li>• Given their role in protecting individuals with developmental disabilities from abuse and neglect, state protection and advocacy agencies are important stakeholders.</li> </ul>
Take statewide action based on mortality information to systematically improve care	<ul style="list-style-type: none"> <li>• When areas of improvement are identified by mortality reviews, state developmental disabilities agencies' actions affect all state providers rather than singling out just one provider.</li> </ul>
Publicly report mortality information	<ul style="list-style-type: none"> <li>• State developmental disabilities agencies publicly report mortality data or mortality review findings, which may include posting such information on the agency's Web site.</li> </ul>

Source: GAO analysis.

Note: To develop this table, GAO analyzed information provided by experts in the field of developmental disabilities and state developmental disabilities agency officials, and performed a literature review.

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States that incorporated additional mortality review components varied in how they implemented them. For example, in Ohio the developmental disabilities agency oversaw its state-level interdisciplinary committee, while in Minnesota the Office of the Ombudsman for Mental Health and Developmental Disabilities provided oversight of its state-level committee, but the committee in Minnesota included a member from the state developmental disabilities agency. In Minnesota, the Office of the Ombudsman, not the state developmental disabilities agency, was also responsible for publicly reporting mortality information on the state's Web site. Appendix II provides detailed information about the more comprehensive mortality review systems in Connecticut, Massachusetts, Minnesota, and Ohio.

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**State-Level  
Interdisciplinary Mortality  
Review Committees  
Conduct Reviews and  
Provide Local Review  
Oversight in 6 of the 14  
States**

In 6 of the 14 states, developmental disabilities agency officials told us that they used state-level interdisciplinary mortality review committees to oversee local review efforts and to add overall value to the review process (see table 4). One aspect of oversight is ensuring consistency in the local-level mortality reviews conducted by developmental disabilities officials across a state. For example, for the purposes of quality assurance, state-level mortality review committees in both Connecticut and Massachusetts reviewed at least 10 percent of cases that local officials had determined did not warrant further review. Massachusetts officials told us that the state's committee reviewed these cases to ensure that its review procedures were followed, these cases were being appropriately closed locally, and there was consistency across the different local levels conducting reviews.

**Table 4: Use of the Four Additional Components for Mortality Reviews by the 14 States, as of December 2007**

Component	States whose officials GAO interviewed													
	Calif.	Conn.	Fla.	Ill.	Iowa	Mass.	Minn.	N.Y.	Ohio	Ore.	Pa.	Tex.	Wash.	Wisc.
Use state-level interdisciplinary mortality review committee (e.g., overseen by developmental disabilities agency)	⊗	●	⊗	⊗	⊗	●	● <sup>a</sup>	⊗	●	⊗	⊗	⊗	●	●
Routinely include external stakeholders in review process (e.g., protection and advocacy agency)	⊗	●	⊗	●	⊗	●	●	●	●	⊗	●	⊗	⊗	⊗
Take statewide action based on mortality information to systematically improve care	⊗	●	●	●	⊗	●	●	●	●	●	●	⊗	●	●
Publicly report mortality information	⊗	●	⊗	⊗	⊗	●	● <sup>b</sup>	⊗	●	⊗	⊗	⊗	⊗	⊗

Source: GAO interviews with state developmental disabilities agency officials.

Legend

- = Implemented this component all the time
- ⊗ = Did not implement this component

Note: These 14 states served approximately two-thirds of Medicaid waiver beneficiaries with developmental disabilities nationally in 2005.

<sup>a</sup>The state-level interdisciplinary committee was overseen by the Office of the Ombudsman for Mental Health and Developmental Disabilities, and its membership included a representative from the state developmental disabilities agency.

<sup>b</sup>The Office of the Ombudsman for Mental Health and Developmental Disabilities, rather than the state developmental disabilities agency, publicly reported mortality information.

In addition, state-level committees examined in greater depth cases that were medically complex or unusual. For example, in Ohio, the state-level committee recently reviewed a case where an individual died suddenly. The individual had multiple medical conditions, including a history of heart disease, and upon review, the committee found that this individual was taking a medication contraindicated for persons who have or had heart problems. The committee issued a safety alert—a notice to community providers to increase their awareness of a particular risk or safety concern—about the use of this medication by individuals with developmental disabilities who have heart conditions.<sup>27</sup> In another

<sup>27</sup>Developmental disabilities agency officials told us they distributed safety alerts by e-mail and postal mail.

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example, the Minnesota state-level review committee reviewed an unusual case where an individual was hospitalized for a minor surgical procedure and discharged. Three days later the individual was readmitted to the hospital with a diagnosis of aspiration pneumonia and an overdose of sedatives and prescription pain medications; after being placed on life support the individual's condition worsened and life support was withdrawn, resulting in death. After review of the death by the state-level review committee, the developmental disabilities agency issued a safety alert, including a recommendation by the committee for improving the care provided to individuals receiving pain medication.

State-level committee reviews were more likely than those at the local level to be conducted by physicians, specifically, physicians with experience treating individuals with developmental disabilities.<sup>28</sup> Of the 6 states that used state-level interdisciplinary mortality review committees, officials in 4 states told us that physicians sat on their committees and routinely reviewed deaths. By contrast, only 1 of the 14 states reported that physicians routinely participated in the local review process. Physician participation is important given the complex medical conditions of individuals with developmental disabilities. For example, Ohio officials told us that it is important for physicians with experience treating individuals with developmental disabilities to review medically complex cases because such physicians are able to assess the adequacy or appropriateness of the medical care provided prior to death. Officials also said that such physicians are highly qualified to evaluate actions taken by other physicians or hospital staff—especially medical personnel without experience caring for individuals with developmental disabilities. For example, one physician serving as Medical Director for a state developmental disabilities agency noted that a death may be inappropriately attributed to natural causes by nonmedical reviewers but a physician's in-depth review of medical records and medication logs could uncover poor care that contributed to the death.

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<sup>28</sup> Oregon and Pennsylvania did not have state-level interdisciplinary mortality review committees, but the Medical Directors for the developmental disabilities agencies in both states reviewed deaths of individuals with developmental disabilities as part of their state-level review process.

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In addition to physicians, state-level interdisciplinary mortality review committees incorporated the knowledge and perspectives of a variety of professionals with differing experiences and responsibility.<sup>29</sup> While physicians and nurses contributed medical and other clinical expertise to the mortality review committees, licensing, public health, investigative, and quality assurance professionals brought other important kinds of expertise. One state official told us that the participation of various types of professionals improved the quality of mortality review findings. Some state officials we interviewed described the value that different professionals brought to mortality reviews. For example, they said that state licensing professionals are best able to assess whether a provider followed state regulations and standards of practice for care. Similarly, an investigator is best suited to evaluate the circumstances of death for possible abuse or neglect. Finally, quality assurance professionals have expertise in monitoring and improving delivery systems and, as a result, can evaluate whether statewide actions may be needed to address identified quality-of-care concerns.

According to the 36 states that completed our e-mail survey, the prevalence of state-level interdisciplinary mortality review committees was similar to that in the 14 states whose officials we interviewed—about half had such a committee (18 of 36 states). Combined, 24 of 50 states reported having a state-level review committee, and 26 did not. The types of members on state-level committees in the 36 states we surveyed were similar to those in the 14 states in which we conducted interviews. Among the 24 of 50 states that we interviewed or surveyed that reported having committees, about 80 percent included physicians or nurses, and 67 percent included quality assurance professionals. Nearly half of all states with committees also reported that they included investigative or forensic professionals as well as representatives from the provider community.

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<sup>29</sup> Another advantage of state-level reviewers is that they are more likely than local reviewers to take a systems-based perspective because of their hierarchical placement within the developmental disabilities agency.

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## Half of the 14 States Routinely Include External Stakeholders in Mortality Reviews, Promoting Independence or Shared Accountability

Seven of the 14 states routinely included stakeholders external to the developmental disabilities agency in their mortality review process. State officials told us they included external stakeholders as a way to promote independence or shared accountability. Four of 7 states used state protection and advocacy agencies regularly for this purpose.<sup>30</sup> For example, in Connecticut an official of the protection and advocacy agency was a member of the developmental disabilities agency's state-level interdisciplinary mortality review committee. In several of these 7 states, other organizations or state offices with a role in protecting and advocating for the rights of individuals with developmental disabilities also participated in the state developmental disabilities agency mortality reviews, or they conducted their own reviews. In Massachusetts, for example, a representative of the Disabled Persons Protection Commission was a member of the agency's state-level interdisciplinary mortality review committee, while in Minnesota the Office of the Ombudsman for Mental Health and Developmental Disabilities—a state office separate from the developmental disabilities agency—independently reviewed each death among individuals with developmental disabilities.

Several developmental disabilities experts and state agency officials told us that external stakeholder involvement in states' mortality review processes can promote independence and shared accountability. According to experts, a natural incentive exists for state agency officials to minimize errors or program weaknesses identified through the mortality review process, making independence important. A federal district court found that the District of Columbia's developmental disabilities agency deleted factual information about eight deaths among individuals with developmental disabilities from death investigation reports in order to minimize quality-of-care concerns.<sup>31</sup> Specifically, information was deleted about delays in obtaining consent for medical procedures and gaps in case management. During our interviews with developmental disabilities agency officials in 14 states, we observed that external stakeholder involvement could also result in shared accountability for improving the quality of care. Because stakeholders may influence how the agency addresses identified quality-of-care concerns, stakeholders may be more

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<sup>30</sup>In addition, state officials in California, Florida, Iowa, and Oregon told us that external stakeholders, such as the state protection and advocacy agencies, were included on an as-needed basis for certain mortality reviews.

<sup>31</sup>*Evans v. Fenty*, 480 F.Supp.2d 280, 310 (D.D.C. 2007).

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likely to support the agency's efforts to improve the quality of care for individuals with developmental disabilities.

The protection and advocacy agencies are of particular value as external stakeholders because of their authority to investigate certain deaths. Moreover, states that receive protection and advocacy funding are required to provide information on the quality of HCBS services to their protection and advocacy agencies, to the extent information is available. We found that state developmental disabilities agencies in 8 of the 14 states were required to report deaths among individuals with developmental disabilities to their state's protection and advocacy agency. The protection and advocacy agencies received notification in several ways, such as on a case-by-case basis or through the distribution of weekly reports of deaths. Developmental disabilities agency officials in 2 states told us that they granted access to their electronic critical incident management system databases to the protection and advocacy agencies in their states. For example, while the protection and advocacy agencies were not notified of all deaths in Pennsylvania and Ohio, protection and advocacy officials told us they could access death reports among individuals with developmental disabilities by monitoring the critical incident database. In 6 of the 14 states in which protection and advocacy officials were not notified of deaths among individuals with developmental disabilities, protection and advocacy agency officials told us that state developmental disabilities agencies should be required to notify their protection and advocacy agencies of these deaths. Protection and advocacy agencies that did not receive notification of deaths relied on the media or concerned family members to alert them of deaths, but such notification was inconsistent and sometimes happened long after the death occurred.

Because abuse and neglect can be difficult to detect among individuals with developmental disabilities, developmental disabilities agency officials may attribute some deaths to known or natural causes, even though abuse or neglect contributed to death. As a result, such cases may not have been referred to investigative authorities, such as medical examiners or the state protection and advocacy agency. One state's protection and advocacy officials told us that their own investigation of a death after notification by a family member identified care concerns that state developmental disabilities agency and law enforcement officials had not detected. Protection and advocacy officials in two other states found neglect when they conducted reviews of two deaths that the states had determined were due to natural causes.

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## Mortality Reviews Result in Statewide Actions to Address Similar Care Concerns and to Help Prevent Deaths in Most of the 14 States

In 11 of the 14 states, mortality reviews resulted in statewide actions to address similar quality-of-care concerns and to help prevent avoidable deaths among individuals with developmental disabilities. The statewide actions resulting from mortality reviews included the issuance of safety alerts, additional or enhanced training of staff, and new risk-prevention practices. The most common statewide action—taken by 9 of the 14 states—was the issuance of safety alerts. For example, after several individuals with developmental disabilities in Minnesota died, in part because of delayed emergency medical care, the agency sent a statewide safety alert to service providers with recommendations to prevent similar incidents, including that community providers authorize their direct care staff to call 911 when they suspect a medical emergency without first obtaining approval from a manager. In Ohio, officials alerted agency staff to an increase, from 2005 to 2006, in the number of deaths statewide resulting from aspiration pneumonia. As a result, these officials encouraged agency staff statewide to closely examine hospitalization cases resulting from pneumonia and to train care providers on risk factors to help prevent this condition.

In 7 of the 14 states, developmental disabilities agencies provided additional or enhanced training to staff statewide, and in 6 of the 14 states they developed new risk prevention interventions for providers statewide. As a result of several choking deaths, the Connecticut developmental disabilities agency developed a training program on swallowing risks that addressed the responsibilities of providers when caring for individuals with swallowing disorders. The agency also required that all direct care staff who provided care to individuals with developmental disabilities receive this training. Based on mortality review findings, Oregon's developmental disabilities agency developed an assessment tool to be completed and regularly updated on individuals with developmental disabilities to identify and properly address risks associated with deaths among this population, including choking, dehydration, constipation, seizures, and falls. Several nurses in Oregon told us that they believed the use of the risk assessment tool had led to improvements in the quality of care provided to individuals with developmental disabilities.

According to responses to our e-mail survey by the other 36 states, 19 state developmental disabilities agencies reported taking a statewide action to improve care based on mortality information. When combined with the 14 states in which we conducted interviews, 30 of 50 states took a statewide action, while 20 did not. The most frequently cited statewide actions nationwide—including the 36 states that completed our e-mail survey—were the issuance of safety alerts, additional or enhanced training of staff,

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and new risk-prevention practices. In total, 60 percent of states nationwide addressed quality-of-care concerns through such actions. Based on examples provided, choking was the most frequently addressed quality-of-care concern nationwide. For example, among states that reported taking a statewide action, 43 percent addressed choking with a statewide action, such as additional training.<sup>32</sup> Other quality-of-care concerns for which multiple states took statewide actions included treating bowel disorders, addressing problems with emergency procedures and medications, and coordinating care across various providers and settings.

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### Four of 14 States Publicly Report Mortality Information

Four of the 14 states publicly reported mortality information by publishing summaries of aggregated data or more detailed reports about their mortality review processes and findings. For example, Ohio annually reported aggregated mortality data on its agency Web site, which included the number of deaths among individuals with developmental disabilities and a list of the most common causes of death. Massachusetts and Connecticut have posted annual mortality reports on their agency Web sites, which included mortality statistics for the population of individuals with developmental disabilities served by their agencies as well as trend analyses of those deaths over time. According to agency officials in Massachusetts, publicly reporting information about mortality review findings helps to ensure transparency in the mortality review process and demonstrates to the public areas where the agency should direct its efforts to improve the quality of care. While 10 of the 14 states we interviewed told us that they do not make their findings publicly available, state officials in California, Pennsylvania, and Washington told us that they had provided such information to select stakeholders or to others when requested.

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### Conclusions

Reviewing the deaths of individuals with developmental disabilities as critical incidents in the Medicaid HCBS waiver program is one of several mechanisms states can use to ensure that this vulnerable population is protected from harm and to address quality-of-care concerns. All 14 states whose officials we interviewed included death among individuals with developmental disabilities as a critical incident in their waiver programs. Nearly all of the 14 states had some processes in place for conducting

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<sup>32</sup>Individuals with developmental disabilities who have swallowing risks often rely on caregivers to prepare special meals, such as pureed foods, and to assist them in eating.

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mortality reviews of individuals with developmental disabilities, even though CMS does not have an expectation for states to review deaths as critical incidents under the waiver program. Most of the 14 states implemented basic components of mortality review processes that experts we interviewed agreed were important, such as the review of unexpected or suspicious deaths. Several states also implemented additional components, such as using a state-level interdisciplinary committee to review individual deaths and routinely including external stakeholders, for more comprehensive mortality review systems. We do not know the extent to which all components were implemented in states we did not interview. However, based on information provided by all states nationwide, (1) 13 states did not aggregate mortality data (a basic component for mortality reviews), (2) 26 states did not utilize an interdisciplinary mortality review committee to review deaths among individuals with developmental disabilities (an additional component), and (3) 20 states had not taken a statewide action to improve care based on mortality review information (an additional component). Moreover, the extent to which states other than the 14 whose officials we interviewed identified death as a critical incident has not been established.

Given the concern that agency officials may minimize identified program weaknesses, routinely including external stakeholders—such as the state office of protection and advocacy—is especially important because it promotes accountability and independence to the state mortality review process. When alerted to suspicious deaths, state protection and advocacy agencies can conduct their own investigations, but not all protection and advocacy agencies were systematically notified of deaths by state developmental disabilities agencies and instead relied on the less consistent or less timely notification of deaths by the media or concerned family members.

Many of the states whose officials we interviewed told us that they considered their mortality review system to be one aspect of their strategy to improve the quality of care in their Medicaid HCBS programs. CMS has recently made some important changes in an effort to clarify its quality expectations for HCBS waivers, such as requesting that states describe their quality improvement strategies as part of the waiver application. In addition, a provision of the Deficit Reduction Act of 2005 requires the development of specific quality measures, and CMS may adopt the measures if it determines that they reinforce the agency's expectations for states regarding quality improvement.

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## Recommendations for Executive Action

To help states identify and address quality-of-care concerns among individuals with developmental disabilities receiving Medicaid HCBS waiver services, we recommend that the Administrator of CMS take the following two actions:

- Disseminate information to states about basic and additional components for mortality reviews.
- Encourage states to
  - include death as a critical incident and conduct mortality reviews if they do not already do so and
  - broaden their mortality review processes if they already include death as a critical incident and conduct mortality reviews.

To provide additional oversight of the quality of care provided to these individuals, we also recommend that the Administrator of CMS establish as an expectation for HCBS waivers that state Medicaid agencies report all deaths among individuals with developmental disabilities receiving such waiver services to their state office of protection and advocacy.

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## Agency Comments and Our Evaluation

We obtained written comments from HHS on our draft report. HHS generally concurred with two of our three recommendations, and did not respond as to whether it agreed or disagreed with one recommendation. HHS's comments are included in appendix III.

In its general comments, HHS stated that not all deaths in the community are adverse events and that the ability to die at home with appropriate supports is a positive outcome. Our report does not state or suggest that all such deaths are adverse outcomes; however, we did report that all deaths of individuals with developmental disabilities served by Medicaid HCBS waiver programs should be screened to determine whether further review is warranted. HHS also stated the importance of ensuring that any actions taken to address our recommendations are applicable to all populations served by HCBS waiver programs (e.g., the aged) and not just individuals with developmental disabilities. While the focus of our report was specifically on individuals with developmental disabilities who are vulnerable and often have complex medical needs, we support HHS's encouraging states to utilize mortality reviews as one aspect of their quality improvement strategy for all populations served by 1915(c) waiver programs.

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Our evaluation of HHS's specific comments on each of our recommendations follows.

**Disseminate information to states about basic and additional components for mortality reviews.** HHS responded that CMS concurred with our recommendation and will disseminate the information through its stakeholders, including the National Association of State Directors of Developmental Disabilities Services, the National Association of State Medicaid Directors, and the National Association of State Units on Aging. HHS also stated that CMS will involve these stakeholders in a discussion on the topic of mortality reviews to help determine whether the six basic components we identified are applicable to other populations served by Medicaid 1915(c) waiver programs.

**Encourage states to include death as a critical incident and conduct mortality reviews if they do not already do so; and encourage states to broaden their mortality review processes if they already include death as a critical incident and conduct mortality reviews.** HHS responded that CMS concurred with this recommendation. However, the agency did not fully address it. HHS's comments state that CMS will initiate a meaningful dialogue with its stakeholders to encourage states' broader use of processes to review suspicious deaths. As noted in our report, however, screening mortality information about all deaths among individuals with developmental disabilities is a basic component of a mortality review system and is necessary to determine whether further review of each death is warranted—including but not limited to those deaths involving suspected abuse or neglect, or that were unexpected. CMS did not directly address part of our recommendation that it should encourage states that do not already do so to include death as a critical incident. We continue to believe that this is important because states are expected to report and review critical incidents and take follow-up actions when a beneficiary is not being safeguarded. In addition, states may use information from their critical incident reviews to identify areas for improving care provided to waiver beneficiaries.

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**Establish an expectation that state Medicaid agencies report all deaths among individuals with developmental disabilities receiving waiver services to their state's office of protection and advocacy.** HHS did not respond as to whether CMS agreed or disagreed with this recommendation but recognized independent third-party reviews as important. HHS also believes it is important that CMS's actions taken to address our recommendations apply uniformly to all populations served by 1915(c) waiver programs. According to a CMS official, the agency's goal is to have a consistent set of expectations for all waiver populations served instead of expectations tailored to specific populations. The elderly would be one such population. Given this goal, HHS commented that it may be difficult to require the reporting of all deaths of individuals being served by these waiver programs to the state offices of protection and advocacy because these offices focus primarily on individuals with developmental disabilities. We continue to believe that the state protection and advocacy agencies are the most appropriate entities for reporting deaths among individuals with developmental disabilities, a vulnerable population that often has complex medical needs. However, in developing a uniform approach to individuals served by waiver programs, we agree that CMS should focus on the benefit of independence in the review process, recognizing that it may not be appropriate for the same entities to be involved for all populations served by waivers.

HHS also provided a technical comment and clarification, which we responded to as appropriate.

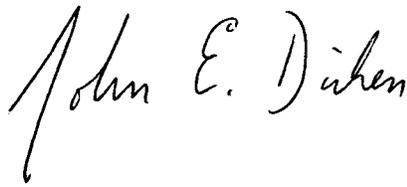
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As arranged with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time, we will send copies of this report to the Secretary of Health & Human Services, the Administrator of CMS, and appropriate congressional committees. We will also make copies available to others upon request. The report will also be available at no charge on the GAO Web site at <http://www.gao.gov>.

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If you or your staff have any questions about this report, please contact me at (202) 512-7114 or [dickenj@gao.gov](mailto:dickenj@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in appendix IV.

Sincerely yours,

A handwritten signature in black ink that reads "John E. Dicken". The signature is written in a cursive style with a large initial 'J' and a distinct 'E'.

John E. Dicken  
Director, Health Care

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# Appendix I: Scope and Methodology

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To assess state mortality review processes for individuals with developmental disabilities served by Medicaid HCBS waivers, we (1) worked with experts in the field of developmental disabilities to identify mortality review components, (2) collected detailed information on death as a critical incident and mortality review processes in 14 states, and (3) conducted a brief e-mail survey focusing broadly on aspects of mortality review processes in the other 35 states and the District of Columbia.<sup>1</sup> We did not evaluate the effectiveness of state mortality review systems. However, the data we collected allowed us to make comparisons across states and to identify states with comprehensive mortality review processes.

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## Identification of Mortality Review Components

To identify basic components of state mortality review processes, we conducted a literature review, interviewed five experts in the field of developmental disabilities, and reviewed documents authored by these experts (e.g., a criteria-and-standards checklist for conducting mortality reviews). These experts were either recommended by CMS officials, referred to us by other officials that we interviewed during the engagement, or were individuals we had contacted during a previous engagement. Along with state developmental disabilities agency officials who conduct mortality reviews, these experts also contributed to the identification of additional components for more comprehensive state mortality review processes. There may be other components for mortality reviews that were not brought to our attention. In addition, these experts guided our selection of states for on-site visits by identifying states they knew to have well-established mortality review processes.

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## Information on Death as a Critical Incident and Mortality Review Processes from 14 States

We collected information and interviewed officials about death as a critical incident and mortality review processes for individuals with developmental disabilities in 14 states. These 14 states served approximately two-thirds of Medicaid waiver beneficiaries with developmental disabilities nationally. The mortality review processes of this sample of 14 states cannot be generalized to all states nationwide.

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<sup>1</sup>We collected information from 50 states, including the District of Columbia. We excluded Arizona because it supported services for individuals with developmental disabilities through a demonstration project waiver under section 1115 of the Social Security Act rather than a home and community-based services waiver under section 1915(c).

First, we visited four states (Connecticut, Ohio, Oregon, and Texas) to gain an understanding of state developmental disabilities systems and mortality review processes and to facilitate the development of interview protocols for the remaining 10 states. We used the following criteria to select these four states: (1) the extent to which a state had a well-established mortality review process, as recommended by experts; (2) the raw number of individuals in a state with developmental disabilities being served by Medicaid HCBS waivers relative to other states; (3) the proportion of all individuals in a state with developmental disabilities receiving services in the community under Medicaid HCBS waivers rather than in institutions, relative to other states; and (4) geographic variation.<sup>2</sup> During the four site visits, we collected and reviewed mortality review documents such as policies and procedures, annual mortality review reports, and health and safety alerts distributed to providers based on mortality review findings. The officials we interviewed included Medicaid directors, developmental disabilities agency medical directors and administrators, members of state mortality review committees, quality assurance and critical incident professionals, or other professionals knowledgeable about the state's mortality review processes. We also interviewed representatives from the state offices of protection and advocacy or other external stakeholders involved in these states' mortality review processes.

Second, to expand our understanding of how states review and use mortality information, we collected similar information from and conducted focused telephone interviews with developmental disabilities officials in the other 10 states that served the largest number of individuals

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<sup>2</sup>We selected Connecticut because it was the state most frequently identified by experts as having a well-established mortality review process. We selected Ohio because experts told us that it also had a well-established mortality review process, had a relatively large number of individuals with developmental disabilities receiving Medicaid HCBS waiver services, and varied geographically from Connecticut. To select our third and fourth site-visit states, we focused on states that (1) had a high proportion of individuals with developmental disabilities being served in the community by Medicaid HCBS waivers rather than in institutions and (2) had geographic variation. We selected Oregon because it ranked in the top 25 percent of all states for the proportion of individuals with developmental disabilities served in the community on waivers, had a large number of Medicaid waiver beneficiaries relative to other states in the top quartile, and was in a different census region and was monitored by a different CMS regional office than Connecticut and Ohio. Finally, we selected Texas for its geographic variation and large number of individuals with developmental disabilities receiving Medicaid HCBS waiver services.

with developmental disabilities through Medicaid HCBS waivers.<sup>3</sup> We also conducted focused telephone interviews with officials from state protection and advocacy agencies in these 10 states and in the District of Columbia.<sup>4</sup>

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## E-Mail Survey to the Remaining 35 States and the District of Columbia

We sent a three-question e-mail survey that focused on three aspects of state mortality review processes to developmental disabilities agency officials in the other 35 states and the District of Columbia. Specifically, we asked agency officials if they had a statewide interdisciplinary mortality review committee, if they aggregated mortality information for this population, and if they had implemented a statewide action based on mortality review findings. We focused on these three issues because of the value identified by experts and state officials in (1) using an interdisciplinary approach to reviewing certain deaths, (2) using aggregated data in addition to individual mortality cases to identify trends or patterns of deaths among individuals with developmental disabilities, and (3) using mortality information to take statewide actions to improve the system of care overall. We followed up with nonrespondents using e-mail reminders and telephone calls, and achieved a 100 percent response rate to our survey.

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<sup>3</sup>These states are California, Florida, Iowa, Illinois, Massachusetts, Minnesota, New York, Pennsylvania, Washington, and Wisconsin.

<sup>4</sup>The District of Columbia was not 1 of the 10 states in which we conducted focused telephone interviews. We contacted this protection and advocacy agency because of local media reports and legal actions directed toward the District's developmental disabilities agency regarding deaths resulting from alleged abuse or neglect among individuals with developmental disabilities living in community residential settings.

# Appendix II: Description of More Comprehensive Mortality Review Systems Implemented by Four States

	Connecticut	Massachusetts	Minnesota	Ohio
<b>Program structure</b>	<ul style="list-style-type: none"> <li>Regional developmental disabilities agency directors oversee operational aspects of the local provision of waiver services to individuals with developmental disabilities. Regional directors report to state's central developmental disabilities office, which provides oversight to the regions.</li> </ul>	<ul style="list-style-type: none"> <li>Four regional developmental disabilities offices manage 23 local area offices responsible for managing and monitoring services provided to individuals with developmental disabilities. State's central developmental disabilities office provides oversight to regional and local area offices.</li> </ul>	<ul style="list-style-type: none"> <li>County-based developmental disabilities officials in 87 county offices provide operational oversight of the local provision of waiver services to individuals with developmental disabilities. State's central developmental disabilities office provides oversight to the counties.</li> </ul>	<ul style="list-style-type: none"> <li>County-level developmental disabilities agency staff oversees the local provision of waiver services to individuals with developmental disabilities. State's central office provides oversight to 88 county developmental disabilities agency offices.</li> </ul>
<b>Components of mortality review process</b>	<ul style="list-style-type: none"> <li>Regional developmental disabilities officials collect and screen standardized information about deaths among persons with developmental disabilities, including demographic information, location and cause of death, and whether the death was anticipated or unexpected.</li> <li>If a death is considered suspicious for abuse or neglect, appropriate authorities are notified to ensure the safety of other community-based residents or to initiate a criminal investigation, as appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>Standard information about deaths among persons with developmental disabilities is collected and screened by area and state-level agency staff. This information includes cause and manner of death, whether the death was unexpected or occurred under suspicious circumstances, the level of mental retardation (including whether the individual had Down's syndrome), and whether or not the medical examiner took jurisdiction over the body.</li> </ul>	<ul style="list-style-type: none"> <li>County-level developmental disabilities officials collect and screen standardized information about deaths among persons with developmental disabilities, including demographic information, location and cause of death, circumstances of the death, and the clinical diagnoses of the deceased.</li> <li>If a death is considered suspicious for abuse or neglect, appropriate authorities are notified to ensure the safety of other community-based residents or to initiate a criminal investigation, as appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>County-level investigative agents for the developmental disabilities agency collect standard information about deaths among persons with developmental disabilities, including location of death, whether the death was unexpected, and circumstances surrounding the death.</li> <li>If a death is considered suspicious for abuse or neglect, appropriate authorities (including the county coroner) are notified to ensure the safety of other community-based residents or to initiate a criminal investigation, as appropriate.</li> </ul>

**Appendix II: Description of More Comprehensive Mortality Review Systems Implemented by Four States**

	<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
		<ul style="list-style-type: none"> <li>If a death is considered suspicious for abuse or neglect, appropriate authorities are notified to ensure the safety of other community-based residents or to initiate a criminal investigation, as appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>The Office of the Ombudsman for Mental Health and Developmental Disabilities also screens standardized information about deaths among persons with developmental disabilities.</li> </ul>	
Types of deaths routinely reviewed ( <i>basic component</i> )	<ul style="list-style-type: none"> <li>All unexpected or suspicious deaths among individuals with developmental disabilities receiving community care by the state developmental disabilities agency are routinely reviewed at a regional level. Nonsuspicious and expected deaths are also reviewed at the regional level.</li> </ul>	<ul style="list-style-type: none"> <li>All unexpected or suspicious deaths among individuals with developmental disabilities receiving more than 15 hours of residential support, or who die in a day support or habilitation program or who die during transportation arranged by the state developmental disabilities agency, are routinely reviewed. Nonsuspicious and expected deaths among this population are also routinely reviewed but at the regional level.</li> </ul>	<ul style="list-style-type: none"> <li>All deaths among individuals with developmental disabilities receiving community care by the state developmental disabilities agency are reviewed at the county and state levels. Deaths under suspicion for involving abuse or neglect are also reviewed by county-based investigators.</li> </ul>	<ul style="list-style-type: none"> <li>All unexpected or suspicious deaths among individuals with developmental disabilities receiving community care by the state developmental disabilities agency are routinely reviewed. Nonsuspicious and expected deaths among this population receive a less-extensive review at the state level.</li> </ul>

**Appendix II: Description of More  
Comprehensive Mortality Review Systems  
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	<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
Medical professionals included in mortality review process ( <i>basic component</i> )	<ul style="list-style-type: none"> <li>Regional reviewers include developmental disabilities nurse investigators and members of the regional mortality review committee, which is composed of (at a minimum) a registered nurse not employed by the developmental disabilities agency, the regional office health services or nursing director, the case management supervisor, the quality improvement director, and a client advocate. In addition, regional reviews may also include the nurse investigator, the former case manager of the deceased, and a nurse involved with the person's care prior to death.</li> </ul>	<ul style="list-style-type: none"> <li>Regional reviewers include developmental disabilities agency nurses and members of the regional mortality review committee, which is composed of (at a minimum) a nurse or physician, or both, and an agency quality assurance professional. In addition, regional mortality review discussions may also include additional regional nurses or area office directors or assistant directors.</li> </ul>	<ul style="list-style-type: none"> <li>County reviewers include primarily case managers but also nurses or other developmental disabilities officials with previous experience providing direct services to individuals with developmental disabilities. These professionals consult with public health nurses or the agency medical director, as needed, to complete their reviews.</li> </ul>	<ul style="list-style-type: none"> <li>County-level investigative agents include registered nurses, case workers, or licensed social workers. These agents consult with physicians on the statewide mortality review committee, as needed, if they have questions during the course of their local-level mortality review.</li> </ul>
Local-level mortality review process ( <i>basic component</i> )	<ul style="list-style-type: none"> <li>Developmental disabilities agency nurse investigators covering the regions conduct desk reviews into the circumstances surrounding the death; interview parties associated with the death; review medical professional progress notes and autopsy reports; and provide this information to the regional mortality review committees in a written report.</li> <li>The regional mortality review committee reviews the overall care, quality-of-life issues, and health care preceding the death of each individual with</li> </ul>	<ul style="list-style-type: none"> <li>Local area nurses conduct desk reviews and complete mortality review forms addressing the circumstances surrounding the death and the overall care provided prior to death, including but not limited to medical and medication histories, functional status of the individual, and information from death certificates and autopsy reports, when available. Local area nurses also interview care providers.</li> </ul>	<ul style="list-style-type: none"> <li>County-level developmental disabilities case managers or other reviewers conduct desk reviews into the circumstances surrounding the death and review medical professional progress notes from the direct care provider(s), when available. These officials share their reviews with county-level developmental disabilities managers.</li> <li>County-level investigators conduct independent reviews of cases that are suspicious for abuse or neglect.</li> </ul>	<ul style="list-style-type: none"> <li>County-level investigative agents collect and review 14 standard pieces of information on each case to determine if the case warrants further review of quality-of-care concerns.<sup>a</sup> This information includes but is not limited to medical diagnoses prior to death; death certificate; narrative surrounding the circumstances of death; at least 72 hours' worth of caregiver notes prior to time of death; medication use; and autopsy findings or coroner's report,</li> </ul>

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	<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
	developmental disabilities. This committee may close the case or refer it to the state-level review committee.	<ul style="list-style-type: none"> <li>The regional mortality review committees discuss the area nurses' reviews and determine if a death should be referred to the state-level mortality review committee.</li> </ul>		<p>as appropriate.</p> <ul style="list-style-type: none"> <li>County-level investigative agents can specifically refer a case to the state-level interdisciplinary committee for discussion.</li> </ul>
Documenting mortality review process, findings, or recommendations ( <i>basic component</i> )	<ul style="list-style-type: none"> <li>The statewide mortality review committee documents and maintains its findings and recommendations on a standard form.</li> </ul>	<ul style="list-style-type: none"> <li>The mortality review committee documents its mortality review process.</li> </ul>	<ul style="list-style-type: none"> <li>The state-level mortality review committee documents its meetings, including the agenda and recommendations.</li> </ul>	<ul style="list-style-type: none"> <li>Findings and recommendations from the mortality review process are documented in the incident tracking system.</li> </ul>
Data aggregation ( <i>basic component</i> )	<ul style="list-style-type: none"> <li>Mortality data are aggregated on the basis of the following factors: cause of death, age, location of death, gender, program service type, the individual's level of functioning, and service delivery provider(s).</li> <li>The state developmental disabilities agency and the mortality review committee review aggregated data and assess trends over time in the leading causes of death among individuals with developmental disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>Mortality data are aggregated on the basis of the following factors: cause of death, age, location of death, gender, and program service type.</li> <li>The state developmental disabilities agency assesses trends over time in the leading causes of death among individuals with developmental disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>Mortality data are aggregated on the basis of the following factors: cause of death, age, and service delivery provider.</li> <li>The state developmental disabilities agency assesses trends over time and analyzes aggregated mortality data.</li> </ul>	<ul style="list-style-type: none"> <li>Mortality data are aggregated on the basis of the following factors: cause of death, age, location of death, gender, program service type, level of functioning, and county.</li> <li>The state developmental disabilities agency and mortality review committee assess trends over time in the leading causes of death for individuals with developmental disabilities.</li> <li>Each county has a designated quality assurance person(s) responsible for identifying and discussing critical incident trends (including deaths) with other county- or state-level quality assurance professionals.</li> </ul>

**Appendix II: Description of More Comprehensive Mortality Review Systems Implemented by Four States**

	<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
Medical and other interdisciplinary professionals included in the state-level mortality review committee ( <i>additional component</i> )	<ul style="list-style-type: none"> <li>Committee membership includes directors of Health and Clinical Services, Quality Assurance, and Investigations for the developmental disabilities agency; the state medical examiner; a physician; a supervising nurse consultant from the Department of Public Health; two individuals appointed by the protection and advocacy agency; and a director of nursing from the developmental disabilities agency.</li> </ul>	<ul style="list-style-type: none"> <li>Committee membership includes the following professionals from the developmental disabilities agency: physicians, nurses, quality assurance officials, and legal staff. Membership also includes representatives from the public health department and investigative unit, pharmacists, and members of the office of protection and advocacy and the stakeholder group Disabled Persons Protection Commission.</li> </ul>	<ul style="list-style-type: none"> <li>Committee membership includes a psychiatrist, forensic pathologist, registered nurse, pharmacist, internist, and a quality assurance official from the state developmental disabilities agency.</li> </ul>	<ul style="list-style-type: none"> <li>Committee membership includes physicians; professionals with expertise in the field of developmental disabilities; state protection and advocacy agency and other advocacy organization representatives; and state agency officials from the critical incident management, quality assurance, and licensure divisions.</li> </ul>
State-level mortality review committee ( <i>additional component</i> )	<ul style="list-style-type: none"> <li>State developed a state-level interdisciplinary independent mortality review committee in 2002 specifically to review deaths of individuals with developmental disabilities.</li> <li>The committee operates at the state level to provide an independent review by qualified professionals unrelated to the deceased and ensures that regional reviewers fully evaluated the health and overall care provided to the individual, including quality-of-life issues. The committee identifies both regional and systemic issues, and makes recommendations and identifies corrective</li> </ul>	<ul style="list-style-type: none"> <li>State established a state-level interdisciplinary mortality review committee in 1999 specifically to review deaths of individuals with developmental disabilities.</li> <li>The committee operates at the state level as part of the developmental disabilities agency's quality management strategy. The committee uses its findings through the mortality review process to improve the quality of care and supports provided by the developmental disabilities agency to persons with developmental disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>State established a state-level interdisciplinary mortality review committee in 1987 to systematically review deaths of individuals receiving services or treatment for developmental disabilities, mental illness, chemical dependency, or emotional disturbance.</li> <li>The committee is overseen by the Office of the Ombudsman for Mental Health and Developmental Disabilities. It is designed to objectively and systematically monitor circumstances surrounding deaths and to provide an opportunity to evaluate quality of care from an individual and</li> </ul>	<ul style="list-style-type: none"> <li>State established a state-level interdisciplinary mortality review committee in 2001 specifically to review deaths of individuals with developmental disabilities.</li> <li>This committee operates at the state level to review all deaths of such individuals to identify and address any case-specific, facility-specific, or systemwide issues that could improve the care provided to other individuals in this community.</li> <li>Physician members of the committee review reports submitted by county-level investigative agents on all deaths and may</li> </ul>

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<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
<p>actions accordingly.</p> <ul style="list-style-type: none"> <li>The committee discusses all cases identified by the regional review committees as needing further discussion and also reviews at least 10 to 15 percent of those cases closed at the regional level for quality assurance purposes—i.e., to ensure consistency in the review process throughout the state and ensure that cases do not escape scrutiny in terms of quality-of-care or systemic issues.</li> <li>The committee meets at least quarterly and more frequently as necessary.</li> </ul>	<ul style="list-style-type: none"> <li>The committee discusses all deaths that meet set criteria for review, including but not limited to those deaths that are sudden, unanticipated, or accidental; or those related to accidental choking, bowel impaction, or an adverse drug event. The committee also reviews any other cases referred to it by the regional committees because of other concerns identified. It also reviews 10 percent of those cases closed at the regional level for quality assurance purposes—to ensure consistency across regions and the closure of appropriate cases—and routinely reviews nonsuspicious or expected deaths.</li> <li>The committee meets every other month.</li> </ul>	<p>systemwide perspective.</p> <ul style="list-style-type: none"> <li>The committee uses established criteria to determine which types of deaths it will review in-depth. For example, it reviews deaths that may have resulted from undiagnosed conditions or delayed medical care as well as those that may be related to abuse or neglect. The committee also reviews cases where family members have requested a review.</li> <li>In contrast to the more in-depth reviews conducted by the committee, a registered nurse within the Office of the Ombudsman reviews all deaths among individuals with developmental disabilities using a less comprehensive procedure.</li> <li>The committee meets monthly.</li> </ul>	<p>close out the case or refer it to the full committee for discussion when quality-of-care concerns are identified. The committee also discusses cases referred to it by county-level investigative agents.</p> <ul style="list-style-type: none"> <li>The committee meets quarterly and reviews mortality information on selected developmental disabilities deaths as well as quarterly and annual trends in mortality.</li> </ul>

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	<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
Process for making information publicly available <i>(additional component)</i>	<ul style="list-style-type: none"> <li>The state makes public its annual mortality review report and other mortality data on its developmental disabilities agency Web site.</li> </ul>	<ul style="list-style-type: none"> <li>The mortality review committee makes mortality information available publicly on its developmental disabilities agency Web site. It distributes mortality information to the Governor's office, advocacy organizations, regional and area developmental disabilities staff, and providers.</li> <li>The mortality review committee also presents its findings annually to the agency's quality councils.</li> </ul>	<ul style="list-style-type: none"> <li>The Office of the Ombudsman makes public a biannual report to the Governor on the Ombudsman's Web site, which includes information on the number of deaths and their causes.</li> </ul>	<ul style="list-style-type: none"> <li>Through an electronic incident tracking system, information about each death, including local- and state-level reviews, is available to providers and developmental disabilities agency professionals across the state and to the state's protection and advocacy agency.</li> <li>Directors' alerts disseminate critical information related to particular deaths to providers and other stakeholders through the electronic incident tracking system and are required to be reviewed by all developmental disabilities agency employees as part of annual training.</li> <li>Basic mortality data are posted on the agency's Web site.</li> </ul>

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Mechanisms for achieving independence by routinely including external stakeholders in mortality review process ( <i>additional component</i> )	<ul style="list-style-type: none"> <li>The state protection and advocacy agency receives information weekly about deaths among individuals with developmental disabilities.</li> <li>By the Governor’s Executive Order, an independent fatality review board was created and is housed in the state’s protection and advocacy agency to conduct independent mortality reviews, “outside” of the developmental disabilities agency.</li> </ul>	<ul style="list-style-type: none"> <li>The state protection and advocacy agency is notified of deaths among individuals with developmental disabilities who were receiving services from the state developmental disabilities agency. The protection and advocacy agency rarely conducts its own investigation of these deaths because of the reviews being conducted by both the developmental disabilities agency and the Disabled Persons Protection Commission, which the protection and advocacy agency helped establish to protect individuals with developmental disabilities.</li> <li>The Disabled Persons Protection Commission is a state government entity independent of the state developmental disabilities agency. It is notified by the agency of all deaths and conducts investigations of some deaths (e.g., unexpected deaths or those considered suspicious for abuse or neglect). A representative from the commission also sits on the agency’s state-level mortality review committee.</li> </ul>	<ul style="list-style-type: none"> <li>The state does not systematically report information about deaths among individuals with developmental disabilities to the state protection and advocacy agency.</li> <li>The protection and advocacy agency can conduct investigations of deaths on a case-by-case basis.</li> <li>The Office of the Ombudsman provides independence to the review of deaths because the office is a state entity independent of the developmental disabilities agency.</li> </ul>	<ul style="list-style-type: none"> <li>The state protection and advocacy agency has direct access to the electronic incident tracking system, which includes information on all deaths among persons with developmental disabilities as well as mortality review information.</li> <li>The protection and advocacy agency and another active developmental disabilities advocacy organization in the state participate as standing members on the statewide mortality review committee.</li> </ul>

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	<b>Connecticut</b>	<b>Massachusetts</b>	<b>Minnesota</b>	<b>Ohio</b>
Statewide actions taken to improve quality of care systemwide, based on mortality review findings ( <i>additional component</i> )	<ul style="list-style-type: none"> <li>In 2006, after several individuals with developmental disabilities died from preventable choking incidents, the developmental disabilities agency initiated a statewide safety campaign with a focus on swallowing disorders as an area of risk. In 2007, the state developmental disabilities agency required that all current direct care staff receive ongoing training on swallowing disorders and that all service delivery providers have internal policies about how they will identify and manage swallowing risks for individuals with developmental disabilities that they serve.</li> </ul>	<ul style="list-style-type: none"> <li>Upon finding a higher mortality rate for female breast cancer in the developmentally disabled population compared with other populations, in 2005 the state developmental disabilities agency began developing computer-based training targeted to direct care staff on preventive screenings, including cancer screenings.</li> <li>Based on reviews of several individuals with developmental disabilities whose deaths involved swallowing disorders, the agency developed protocols in 2006 on how to treat swallowing disorders and trained direct care staff on symptoms and treatment.</li> </ul>	<ul style="list-style-type: none"> <li>In 2007, after several individuals developed a serious condition or died prior to receiving treatment, the developmental disabilities agency sent an alert to service providers with recommendations to reduce the likelihood of similar incidents. For example, the alert recommended that programs authorize caregivers to call 911 without approval from a management staff person when a medical emergency is suspected.</li> </ul>	<ul style="list-style-type: none"> <li>The state's developmental disabilities agency issued a safety alert on choking in 2006 because of concerns about an increased number of deaths from choking that occurred in 2006 compared with 2005. Based on a trend in unplanned hospitalizations related to pneumonia, and higher death rates from aspiration pneumonia than in previous years, the agency issued a safety alert in 2006 about pneumonia and encouraged the use of vaccinations to prevent similar deaths.</li> </ul>

Source: GAO analysis.

Note: To develop this table, GAO analyzed information provided and verified by state developmental disabilities agency officials in Connecticut, Massachusetts, Minnesota, and Ohio.

\*For the following types of deaths, investigative agents collect and review 4 rather than 14 pieces of standardized information: persons residing in a facility (e.g., nursing home or intermediate care facility for the mentally retarded licensed by agencies other than the developmental disabilities agency); children and adults who had been living at home and died while in the hospital; and persons with cancer or who died while receiving hospice services.

# Appendix III: Comments from the Department of Health & Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Assistant Secretary  
for Legislation

Washington, D.C. 20201

MAY 01 2008

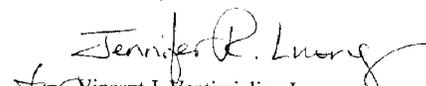
Mr. John Dicken  
Director, Health Care  
Government Accountability Office  
441 G Street, NW  
Washington, DC 20548

Dear Mr. Dicken:

Enclosed are the Department's comments on the U.S. Government Accountability Office's (GAO) Draft Report, "MEDICAID HOME AND COMMUNITY-BASED WAIVERS: CMS Should Encourage States to Conduct Mortality Reviews for Individuals with Developmental Disabilities" (GAO-08-529).

The Department appreciates the opportunity to review and comment on this report before its publication.

Sincerely,

  
Vincent J. Ventimiglia, Jr.  
Assistant Secretary for Legislation

Attachment

**GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE U.S. GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT ENTITLED: "MEDICAID HOME AND COMMUNITY-BASED WAIVERS: CMS SHOULD ENCOURAGE STATES TO CONDUCT MORTALITY REVIEWS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES" (GAO 08-529)**

The Department appreciates GAO's attention to home and community-based services (HCBS) waivers and CMS' efforts to ensure the well-being of individuals served. This report provides useful information regarding the approaches utilized by waiver programs serving individuals with intellectual disabilities and developmental disabilities (ID-DD) relative to mortality reviews for those specific disability populations.

While your report expressly targets individuals with mental retardation and developmental disabilities, the 1915(c) waiver program includes a broader scope of participants who require long-term care and who meet the requirements for an institutional level of care. In our mission to assure that individuals with disabilities have access to independent living in settings of their choice, we reinforce and encourage the GAO to recognize that all deaths in the community are not adverse events; in fact, the ability to die at home with appropriate supports is a positive outcome. Deaths that occur from poor quality services and supports, or the absence of necessary services and supports, are adverse events that we expect State waiver programs to identify and address.

In reviewing the recommendations and determining our responses, we considered the importance of assuring that our actions were applicable to all populations served in the 1915(c) waiver program, including but not limited to, those with ID-DD. Your recommendations and our responses are provided below.

**GAO Recommendation**

The GAO recommends that CMS disseminate information to States about the components of mortality reviews and encourage States to conduct mortality reviews or broaden existing mortality review processes.

**HHS Response**

The CMS concurs with this recommendation and will disseminate information through our stakeholders, including the National Association of State Medicaid Directors, the National Association of State Directors of Developmental Disabilities Services, and the National Association of State Units on Aging, and engage them in a discussion regarding this topic. Since the 2003 GAO report, CMS has actively engaged States and the Associations in the development and design of mechanisms to improve the quality in home and community-based services waivers. This approach has yielded significant improvements in the 1915(c) waiver application process, the waiver quality review process, as well as the process for providing technical assistance to States regarding their quality improvement strategies. Furthermore, this approach has enabled the development of policies that apply to all populations served in the 1915(c) waiver program, while providing States the flexibility to design elements specific to meet the needs of particular populations.

**GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE U.S. GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT ENTITLED: "MEDICAID HOME AND COMMUNITY-BASED WAIVERS: CMS SHOULD ENCOURAGE STATES TO CONDUCT MORTALITY REVIEWS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES" (GAO 08-529)**

The CMS will utilize this forum to gain necessary information regarding the costs of mortality review processes, as well as the identification of strategies that may be used for populations other than ID-DD. CMS will utilize this approach to determine whether the GAO-identified six basic mortality review components have general applicability to persons with physical disabilities, persons who are aging, persons with terminal illnesses, and other populations served by the HCBS waiver program.

In summary, CMS will initiate a meaningful dialogue to encourage the broader use of processes to review suspicious deaths as an important element of a State's overall Quality Improvement Strategy for the waiver.

**GAO Recommendation**

The GAO recommends that CMS establish an expectation that States report all deaths to State protection and advocacy agencies.

**CMS Response**

The protection and advocacy systems contained in each State emanate from the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (also known as the DD Act). These programs are administered by the Administration on Developmental Disabilities. The DD Act provides for a program to support a Protection & Advocacy (P&A) System in each State, and Territory, as well as a Native American Consortium, to protect and advocate for persons with developmental disabilities. All States, Territories, and a Native American Consortium (total of 57) are funded under the Protection & Advocacy for Individuals with Developmental Disabilities (PADD) program that requires the governor to designate a system in the State to empower, protect, and advocate on behalf of persons with developmental disabilities. This P&A system implementing the PADD program must be independent of service-providing agencies.<sup>1</sup> As these entities focus primarily on individuals with developmental disabilities and, in some States, individuals with chronic mental illness, it may be difficult for CMS to require this uniformly. However, the GAO's message regarding the importance of independent, third-party review is important. In our discussions with the aforementioned stakeholders, CMS will collaborate with them regarding strategies to effectuate a system of independent review across waivers and for various populations.

In closing, HHS would like to thank the GAO and its staff for this informative report. We appreciate the GAO's continued interest in the HCBS waiver program and for the vigilance in ensuring that strong systems are in place to guarantee the health and welfare of all vulnerable populations served through the program.

<sup>1</sup> Administration on Developmental Disabilities. State Protection and Advocacy Agencies Systems Fact Sheet 12/06/06

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# Appendix IV: GAO Contact and Staff Acknowledgments

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## GAO Contact

John E. Dicken, (202) 512-7114 or [dickenj@gao.gov](mailto:dickenj@gao.gov)

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## Acknowledgments

In addition to the contact named above, key contributors to this report were Walter Ochinko, Assistant Director; Stefanie Bzdusek; Pamela Dooley; Sara Imhof; Elizabeth T. Morrison; and Andrea E. Richardson.

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