Investigation of Deaths

In Facilities Owned or Operated by the Commonwealth of Kentucky

1999—2002

Commonwealth of Kentucky
Protection and Advocacy
100 Fair Oaks Lane
Frankfort, KY 40601
(502) 564-2967
1-800-372-2988
(TTY and toll free)

Investigation of Deaths in Facilities Owned or Operated by the Commonwealth of Kentucky 1999-2002

Kentucky Protection & Advocacy
January 2004

TABLE OF CONTENTS

Abstract 2

Introduction 3

Methodology 3

Why institutional deaths may not be fully investigated 4

Identifying suspicious deaths 5

State mortality review committee established 6

Recommendations and summary 7

Appendix A—Investigation instrument 9

Appendix B—Case study scenarios 11

- Individual A 11
- Individual B 11

Appendix C—Flow chart for mortality review 13

Abstract

This report chronicles the results of a four-year effort by Kentucky Protection and Advocacy (P&A) to establish a state-wide death reporting and review system in facilities where people with developmental disabilities and mental illness live that are owned or operated by the Commonwealth of Kentucky.

Introduction

Protection and Advocacy is Kentucky's federally mandated program that protects the rights of citizens with disabilities in the Commonwealth of Kentucky. Federal laws charge all P&As to investigate abuse and neglect of individuals with mental illness[1] and developmental disabilities[2] who live in facilities.[3] This charge includes investigating deaths resulting from abuse and neglect.

In September 1998, responding to reports of widespread deaths in Connecticut caused by misuse of restraints in facilities,[4] P&A began discussing how to better address the problem of deaths in general, and restraint-related deaths in particular, in state-owned or -operated facilities. Prior to this time, Kentucky P&A investigated each death that came to its attention on a case-by-case basis, if the facts warranted; P&A was concerned, however, that neither state agencies nor facilities always informed us of facility deaths.[5]

As a result of these discussions, P&A formed the Death Investigation Group (DIG) to analyze existing mechanisms for death reporting and review in state-owned or -operated facilities, and to advocate for a thorough, state-wide reporting and review system. This report chronicles the results of that four-year effort. The focus population was made up of people with developmental disabilities and mental illness. The effort was funded out of the federal grant awards to the Protection and Advocacy for Developmental Disabilities Program (PADD)[6] and the Protection and Advocacy for Individuals with Mental Illness Program (PAIMI).[7] The leader of DIG was Marsha Hockensmith, Federal Program Coordinator. Team members included Bill Stewart, PAIMI Federal Program Coordinator, Jan Powe, Advocate, Ken Zeller, Legal Director and John Basham, consumer.

Methodology

Preliminary investigation revealed there was no central registry of deaths at the state level in Kentucky.[8] Indeed, there was no single uniform instrument used for reporting deaths in state-owned or -operated facilities. Reporting to any authority outside the facility was sporadic and not required by the state department responsible for operation of these facilities, the Kentucky Department for Mental Health and Mental Retardation (DMH/MR).[9] There was no state level morbidity and mortality review. Facilities were left to their own devices in conducting such reviews. In some facilities nothing more than a chart entry was made. In most, an in-house committee convened to review the circumstances of a resident's death, but the results did not leave the committee room.

The Death Investigation Group concluded that a formal review system of state facility deaths needed to be created. The focus of DIG's efforts would be to establish a formal review system of psychiatric hospitals, intermediate care facilities for persons with mental retardation (ICFs/MR) and nursing homes. The desired outcomes would be to

1. establish a database of information on all deaths in state-owned and operated facilities from 10-1-98 to 10-1-99;
2. identify trends and patterns in facility deaths;
3. identify individuals who were most at risk of death with an emphasis on seclusion and restraint;
4. encourage DMH/MR to issue a universal policy or protocol to be used by all facilities in death cases;
5. advocate for DMH/MR to establish and maintain a central registry of all deaths in facilities;
6. provide state officials and family members the results of DIG death investigation results for appropriate follow-up action; and
7. secure an agreement with DMH/MR to notify P&A of all facility deaths.

The Death Investigation Group negotiated at length with DMH/MR and its Office of General Counsel regarding P&A's legal authority to access the information necessary to carry out this effort.[10] The General Counsel was reluctant to allow P&A access to any information that was not incidental to a specific individual about whom P&A had received a complaint or had probable cause to believe may have been subjected to abuse or neglect. After much discussion, the General Counsel agreed to the voluntary release of the records of such individuals.

Why institutional deaths may not be fully investigated

Deaths in state facilities where people with mental illness and mental retardation live occur for all the same reasons that deaths occur in private facilities and in the general population. Usually, facilities will report a death to the appropriate authorities if the death occurs under obviously unusual or suspicious circumstances.

This results in an investigation by one or more of three entities with overlapping jurisdiction: the Health and Family Services Cabinet (HFSC) Adult Protective Services Division (APS); the HFSC Licensing and Regulation Division (L&R); and the local or state law enforcement agency.[11]

Scrutiny of deaths that are not obviously unusual are frequently cursory in nature or non-existent. This may be due to the nature of the population in state facilities and the fact that many residents do not have involved families or guardians. When the circumstances of a resident's death involve such dramatic facts as being scalded in a bathtub or overdosed with medication, that death likely will be scrutinized. Less obvious circumstances are often ignored or summarily dismissed as non-contributory to the death, without further probing or reflection. Coroners' reports frequently are inconclusive because of the inherent difficulties in establishing a definitive cause of death, lack of sophisticated testing equipment or because the local coroner is not sufficiently trained to detect elusive causes. The Death Investigation Group believes that critical factors may be overlooked or misunderstood. A structure for accountability, then, is all the more necessary, given the vulnerable nature of the population involved.

Identifying suspicious deaths

Experience indicated to DIG that residents who die at younger ages, with or without significant physical medical problems, often have had histories replete with substantial numbers of incident reports, including having been subjected to recurrent use of physical restraints and seclusion, chemical restraints, drugs prescribed in combination, and overuse of as needed or PRN medications.[12] Staff persons are often unfamiliar with risk factors in a patient's history. Behavior management plans have not been implemented. Finally, understaffed shifts and under-trained and inattentive staff persons are problems that frequently have been identified. The Death Investigation group believes that the existence of these indicia of suspiciousness should trigger increased scrutiny of a resident's record. The circumstances of such deaths should be examined by persons with particular expertise in the forensics associated with mortality in institutionalized individuals.

To determine whether deaths occurring under these circumstances were being investigated as suspicious deaths, DIG reviewed each facility's death review policies then randomly reviewed records of deceased persons.

First, DIG scrutinized each facility's policies about reviewing and reporting facility deaths. The Death Investigation Group found that facilities had no systematic method of reporting deaths to DMH/MR. Many times a telephone call by a facility

to DMH/MR was the extent of reporting. The Department of Mental Health and Mental Retardation did not require specific information about deaths nor did it collect or maintain data on deaths that could identify patterns or trends. No uniformity for mortality reviews existed among facilities.

Next, DIG developed an instrument for recording data extracted from the records of deceased persons.[13] Team members were assigned to randomly review records of deceased individuals and fill out the instrument.[14] The Death Investigation Group reviewed records of fifty-five deaths that occurred from October 1998 through October 2000 and entered the results of this review into a database that now comprises the baseline against which DIG measures subsequent suspicious deaths and identifies trends.[15]

What DIG found was that conditions such as polypharmacy, overuse or improper use of seclusion or restraints, lack of staff familiarity with a patient's history or risk factors, and poorly trained or inattentive staff frequently did not trigger increased scrutiny of facility deaths by DMH/MR.

State mortality review committee established

At the same time, DIG was securing and working with death data, it worked to ensure that the state of Kentucky would set up a central registry of deaths and some meaningful review process outside the facilities. The team leader met many times with DMH/MR officials, principally the clinical director of mental health and mental retardation services, until DMH/MR agreed to establish the Central Office Mortality Review Committee.[16]

The Central Office Mortality Review Committee is a state government body chaired by the clinical director for MH/MR services, although it is not truly an independent investigatory body. Facility clinical directors and deputy commissioners serve as committee members. The Commissioner of Mental Health and Mental Retardation has charged the Mortality Review Committee to review all deaths in state-owned or -operated facilities. When reviewing deaths, the committee looks at

1. whether seclusion and chemical or physical restraints were used;
2. medication errors, which include multiple as needed or PRN medications administered close in time to each other; and
3. the general medical condition of the patient.[17]

As recommended by P&A, DMH/MR adopted

1. uniform reporting requirements;
2. timelines under which investigations must be completed; and
3. a statewide database to track trends.

In addition to serving as a member of the Mortality Review Advisory Committee, P&A now receives reports of all deaths in state-owned and -operated facilities from individual facilities. Protection and Advocacy may perform in depth analyses of deaths that exhibit the above indicia of suspiciousness. When investigating a death, P&A reviews a more complete set of records and compiles data using the spreadsheet that permits DIG to track patterns.

Recommendations and summary

As noted above, in DIG's experience, facility deaths with obvious indicia of suspiciousness are usually referred by the state to the appropriate investigatory body. When deaths occur in public facilities, however, there is no automatic investigation, nor mortality review conducted by the state's Office of Inspector General or Adult Protective Services. State guardianship rarely, if ever, requests an autopsy. Coroners are hesitant to request an autopsy due to financial burden. Often coroners' offices are not involved as facility doctors sign the death certificates. Therefore, P&A will continue to monitor the state's disposition of state facility death cases. If a facility death is not referred to the appropriate investigating agency and DIG believes there are indicia of suspiciousness surrounding it, P&A will either make the referral or initiate its own investigation.

The Mortality Review Committee process now in place gives more assurance that questionable deaths will be identified and that facilities or parts of facilities with questionable practices or habits will come to the attention of state officials. Protection and Advocacy urges that the mortality review process currently in place for state-owned or -operated facilities be extended to state-owned or -operated personal care homes and supports for community living programs, as planned by the Mortality Review Committee.

An automatic review at the Department level is the preferred way to determine whether facility deaths are natural occurrences or the result of specific abuse or neglect. As opposed to internal reviews conducted by individual facilities, this impartial forum can identify practices such as polypharmacy, overuse or improper use of seclusion or restraints, lack of staff familiarity with a patient's history or risk

factors, and poorly trained or inattentive staff. The implementation of this review process is a strong indication of the state's commitment to a consistently high standard of care in all its facilities.

Appendix A—Investigation instrument

REVIEW TOPICS FOR CASE REVIEWS OF DECEASED CLIENTS

Name____________________SS#____________________DOB__________________

Diagnosis/Disability____________________ Closest Relative____________________

State/Private Guardian Y N_________________________

Address______________________

Phone________________________

Name of Social Worker or QMRP____

Facility_________________________ Unit or Ward ___________________________

Name of Doctor__________________ Date of Admission_______________________

Medications____

Summarize PRN Medications____

List of Medications and Times Given Prior to Death:____________________________

____

Any Medical Issues____

Recent Evaluations/Consults____

Seclusions/Restraints____

Review Most Recent Treatment Plan (Any notable information)___________________

____

Review Behavior Modification Plan (Any notable information)____________________

____

Incident Reports Requested (Summarize or Attach)_____________________________

____

Cause of Death__________________ Date of Death_________ Time of Death_______

Coroner's Report (Summarize)____

Autopsy Report Requested? Y N (Summarize)_________________________________

Adult Protective Services Involved? Y N (Summarize or Attach)__________________________________

Licensing & Regulation Involved? Y N (Summarize or Attach)_________________________________

Police Involved? Y N (Summarize or Attach)_________________________________

Witnesses Interviewed____

____

Issues Requiring Review by Medical Professional______________________________

Summarize Issues of Concern____

____

Appendix B—Case study scenarios

For purposes of this report, the individuals will be referred to as Individual A and Individual B.

Individual A

Individual A was a middle-aged man with developmental disabilities including mental retardation, cerebral palsy and pica, which is a disorder characterized by eating things that are not food. He had lived in a public institution for several years. Staff persons were to monitor him closely because of his pica and not leave inedible items within reach.

On the day of his death, facility staff persons noticed he appeared to be choking. They checked his mouth for foreign objects, did a finger sweep, and then performed the Heimlich maneuver. Eventually Individual A became unconscious, and staff began cardiopulmonary resuscitation (CPR). When the ambulance arrived, rescue workers intubated Individual A and retrieved a foreign object form his throat: a latex glove. They transported him to the local medical center where he later died. The glove had been left on a lap tray within Individual A's reach.

Individual B

Individual B was another middle-aged man who had severe mental retardation and seizure disorder. He had lived in a public institution for more than ten years. On the evening he died, staff reported that he ate his evening meal and had not complained of feeling badly. He then went to bed.

At night, facility policy requires hourly bed checks be performed from 11:00 p.m. until 7:00 a.m. A bed check requires a staff person to check on the resident and make sure the resident is warm, dry and breathing. Staff recorded hourly bed checks of Individual B throughout the evening and early morning hours.

Around 6:00 a.m. the next morning, staff noticed that Individual B was not breathing and began CPR. Attempts to revive him were unsuccessful. The coroner was called and arrived at the facility around 7:00 a.m. that morning. He estimated Individual B's body was in the sixth hour of rigor mortis, noting that Individual B had probably died much earlier than 6:00 a.m. This raised the question of whether

hourly bed checks had, in fact, been conducted. A video camera revealed that one staff person claiming to have conducted bed checks never left the living area of the cottage during the shift.

Appendix C—Flow chart for mortality review

Step 1. All deaths are reviewed by the facility Mortality Review Committee using the completed data collection form. Findings forwarded to the facility peer Review Committee for their consideration and recommendations.

Step 2. Peer Review Committee reviews the finding and makes their own recommendations and comments and forwards this to Medical Executive Committee.

Step 3. The Medical Executive Committee reviews, makes their comments and recommendations and forwards their findings to the Facility Director.

Step 4. The facility director forwards the data collection forms, minutes of the facility Mortality, Peer Review Committee and the Medical Executive Committee to the Central Office Mortality Review Committee.

The Central Office Mortality Review Committee shall establish a subcommittee for the following: the psychiatric hospitals, the nursing facilities and the ICF/MR [sic] facilities. Each subcommittee will be chaired by a member of the Central Office Mortality Review Committee and other members of each of the subcommittee [sic] will be appointed by the chairperson of the Central Office Mortality Review Committee and membership will consist of individuals from their respective areas. The subcommittees will review all of the information from their respective areas. The state run/contracted personal care home finding will be reviewed by the hospital subcommittee and the findings from the supported community living facilities will be reviewed by the ICF/MR [sic] subcommittee.[18] The chairperson of the subcommittees will present the findings to the Central Office Mortality Review Committee.

Step 5. The Central Office Mortality Review Committee reviews all the data collection forms, recommendations and comments from the facilities and consider [sic] all the findings and how they fit into the existing guidelines.

The Central Office Mortality Review Committee may use the following process:

a. If all criteria are met and there are no extenuating circumstances the facility Mortality Review Committee is notified through the facility director. The information is forwarded to the data bank for aggregation of data and comparison of department data to the statewide and national information base. If certain criteria are not met then the facility director will be informed by memorandum or a corrective action form for follow-up.

b. If findings fall into previously identified criteria such as:

    1. Death occurring with patient in seclusion/restraint

    2. Death associated with medication error

    3. Polypharmacy as a contributing factor

    4. Unexpected death with or without extenuating circumstances

    5. Special interest situations

    All of these deaths are referred to the special consultants for review and recommendations. The findings are reported to the Central Office Mortality Review Committee for further follow-up through the usual process.

c. General information and findings are forwarded to the Commissioner's Office for comment, if any. If further review is recommended then this request will be forwarded to the special consultants for their review and recommendations with findings being sent to the Central Office Mortality Review Committee for their consideration.

Step 6. General information and aggregation of data showing trends and patterns will be shared with the Mortality Review Advisory Committee[19] for their information and comments.

---

[1] Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act 42 U.S.C. §§ 10801 to 10807. *See* 42 U.S.C. § 10805(a).

[2] Developmental Disabilities Assistance and Bill of Rights (PADD) Act 42 U.S.C. §§ 15001-15115. *See* 42 U.S.C. § 6042(a)(2)(B).

[3] *See Alabama Disabilities Advocacy Program v. J.S. Tarwater Developmental Center*, 97 F.3d 492 (11th Cir. 1996).

[4] Eric M. Weiss, *Deadly Restraint: A Nationwide Pattern of Death*, Hartford Courant, October 11- 15, 1998. The report is available on the paper's web site beginning at <http://courant.ctnow.com/projects/restraint/day1.stm>. The Hartford Courant reported facility deaths from asphyxia and cardiac complications due to restraint and seclusion use, drug overdoses and interactions, blunt trauma, strangulation or choking, fire and smoke inhalation, and breathing vomit into the lungs (aspiration).

[5] Piecemeal governmental review and reporting requirements concerning facility deaths is a nationwide problem, causing the numbers of suspicious facility deaths to be greatly underreported. See *Extent of Risk from Imrproper Restraint or Seclusion Unknown,* U.S. Government Accounting Office Publication GAO/T–HEHS–00–026, 6-8, available at <http://www.gao.gov/new.items/he00026t.pdf>.

[6] 42 U.S.C. §§ 15043-15115.

[7] 42 U.S.C. §§ 10805 to 10807.

[8] Facilities, however, must report any death related to abuse or neglect to Adult Protective Services. See footnote 11, below.

[9] K.R.S. § 194A.030(4).

[10] *See Advocacy, Inc. v. Tarrant County Hospital District*, 2001 WL 1297688 (N.D. Tex. October 11, 2001); *Georgia Advocacy Office v. Borison*, 520 S.E.2d 701 (1999); and *Alabama Disabilities Advocacy Program v. J.S. Tarwater Developmental Center*, 97 F.3d 492 (11th Cir. 1996).

[11] Under K.R.S. § 194B.010 and following, the Health and Family Services Cabinet (formerly the Cabinet for Families and Children) provides child and adult protective services in Kentucky, which include investigating abuse and neglect allegations. However, K.R.S. §194.030(5)(b) authorizes OIG to license and regulate health

facilities. Its duties also include investigating abuse and neglect allegations and suspicious deaths in facilities. Typically, APS defers to OIG when an abuse or neglect allegation arises in a state-owned or -operated facility. Each agency must notify the appropriate law enforcement agency of abuse and neglect referrals and must work with law enforcement to investigate those allegations.

[12] An investigation of restraint- and seclusion-related deaths by the United States Government Accounting Office noted the following:

Restraint and seclusion can be dangerous to individuals in treatment settings because restraining them can involve physical struggling, pressure on the chest, or other interruptions in breathing. [The Joint Commission on the Accreditation of Healthcare Organizations] reviewed 20 restraint-related deaths and found that in 40 percent the cause of death was asphyxiation, while strangulation, cardiac arrest, or fire caused the remainder.

. . . .

People are at particular risk if they have a combination of conditions, such as both mental retardation and mental illness, or mental illness and substance abuse. People with both mental illness and mental retardation often are not in specialized programs to address their unique needs and instead may be placed in either psychiatric hospitals or facilities for people with mental retardation only.

. . . .

Many advocates we spoke with indicated that restraining individuals who are on certain medications can be risky. For example, a commonly prescribed antidepressant may result in metabolic problems when a patient's movement is restricted, which may lead to life-threatening hyperthermia. Clinicians have postulated that potentially fatal cardiac arrhythmia can result from the combination of certain drugs and the adrenaline produced by an individual's agitation and physical struggle while being restrained.

Improper Restraint and Seclusion Places People at Risk, U.S. Government Accounting Office Publication GAO/HEHS–99–176, 6-8, available at <http://www.gao.gov/archive/1999/he99176.pdf>.

[13] *See* Appendix A.

[14] *See* Appendix B for examples of deaths with indicia of suspiciousness as discovered through this survey process.

[15] Protection and Advocacy continues to review and investigates facility deaths using this database.

[16] This proved to be a time-consuming process that requires continued vigilance to this day to ensure that the process does not break down.

[17] *See* Appendix C.

[18] Deaths occurring in personal care homes will be reviewed by the psychiatric hospital subcommittee. Deaths occurring in supports for community living programs will be reviewed by the ICFs/MR subcommittee.

[19] The Mortality Review Advisory Committee membership includes the following: the Director of Clinical Services for DMH/MR; the Deputy Commissioner for DMH/MR facilities; a member from the Central Office Mortality Review Committee; a member from Protection and Advocacy; and individuals with a disabilities.