



District of Columbia
Mental Retardation and Developmental
Disabilities
Fatality Review Committee
Annual Report
2001, 2002 and 2003



Presented to

Government of the District of Columbia
Anthony A. Williams
Mayor

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City Administrator/Acting Deputy Mayor for Public Safety and Justice

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October 2004


The Honorable Mayor Anthony A. Williams
Honorable Members of the Council of the District of Columbia

On behalf of the Mental Retardation and Developmental Disability Fatality Review Committee, we are pleased to present the Annual Report covering statistical data and recommendations resulting from fatality reviews held during calendar years 2001 through 2003.

This report presents recommendations we believe address and provide solutions to systemic issues as they relate to services provided to this community. It will serve as an indicator to aid the District in providing superior services and coordination of care for this vulnerable population.

As we strive to improve the overall quality of care that residents who are developmentally disabled receive in the District of Columbia, we encourage citizens to join us in our efforts to make the District of Columbia the model for the rest of the nation in providing this service

Sincerely,


Marie-Lydie A. Pierre-Louis, MD
Interim Chief Medical Examiner
Office of the Chief Medical Examiner


Dale Brown
Administrator, MRDDA
MRDD FRC Co-Chair

Executive Summary

This is a report of the District of Columbia Mental Retardation and Developmental Disability Fatality Review Committee for 2001, 2002, and 2003. The Mental Retardation and Developmental Disability Fatality Review Committee was established in February 2001, by Mayor's Order 2001-27, (herein after referred to as the Order). The Order mandates that the Committee, referred to as the Fatality Review Committee, examine events that surround the deaths of District wards or residents 18 years of age and older with mental retardation and/or developmental disabilities.

The Fatality Review Committee is comprised of members who represent public and private community organizations from a broad range of disciplines to include health, mental health and mental retardation, social services, public safety, legal and law enforcement. These individuals come together as a collective body for the purpose of examining and evaluating relevant facts associated with services and interventions provided to deceased persons with mental retardation and developmental disabilities.

During the fatality case reviews, the Fatality Review Committee examines an independent investigative report of each individual's death and a forensic autopsy report. The reports highlight each deceased individual's social history including family and care giver relationships and living conditions prior to death; medical diagnosis and medical history; services provided; and cause and manner of death. These fatality reviews may lead to identification of systemic health care and service concerns. The Fatality Review Committee recommends strategies to promote comprehensive health care and improve the quality of life for persons with mental retardation and developmental disabilities.

Recommendations made by the Fatality Review Committee, during the period covered by this report related to coordination of care, case record documentation, and end of life issues. The recommendations have impacted policy, legislative principles, clinical practice, community resources, and city budget allocations.

Introduction

This report is a composite summary of work of the District of Columbia Mental Retardation and Developmental Disability (MRDD) Fatality Review Committee for the calendar years 2001, 2002 and 2003. The MRDD Fatality Review Committee was established in February 2001, by Mayor's Order 2001-27, (herein referred to as the Order). The Order mandates that the Committee, referred to as the Fatality Review Committee (FRC), examine events that surround the deaths of District wards or residents 18 years of age and older with mental retardation and/or developmental disabilities. See Appendix A for the full text of the Order.

The Mental Retardation and Developmental Disabilities Administration (MRDDA) facilitates services and resources for persons with mental retardation and/or developmental disabilities in the District of Columbia. Mental retardation is defined as a condition of substantial limitation in capacity that manifests before 18 years of age and is characterized by "significantly subaverage general intellectual level" existing concurrently with two (2) or more significant limitations in adaptive functioning. See Appendix B for relevant DC Law.

The FRC is comprised of members who represent public and private community organizations from a broad range of disciplines to include health, mental retardation and mental health, social services, public safety, legal and law enforcement. These individuals come together as a collective body for the purpose of examining and evaluating relevant facts associated with services and interventions provided to deceased persons with mental retardation and developmental disabilities (MRDD).

During the fatality case reviews, the FRC examines an independent investigative report and a report of a forensic autopsy conducted by the Office of the Chief Medical Examiner. The reports highlight each deceased individual's social history including family and care giver's relationships with the deceased, and living conditions prior to death; medical diagnosis and medical history; services provided; and cause and manner of death. These fatality reviews examine compliance with regulations and recommendations by service providers, and may lead to identification of systemic health care and service concerns. The FRC recommends strategies to promote comprehensive health care and improve the quality of life for persons with MRDD.

This report is organized as follows: (1) Duties of the committee; (2) Demographic characteristics of deceased persons with MRDD; (3) Place of death; (4) Residence at time of death; (5) Cause and Manner of death; and (6) Highlights and a Look Forward.

Duties of the Committee:

The duties of the Committee as set forth in the Order are:

- Expediently review deaths of residents living in group homes, foster homes, nursing homes or any other health care entity licensed by and located in the District of Columbia*;
- Identify the causes and circumstances contributing to deaths of District wards (DW) or residents with mental retardation, developmental disability or other disabling conditions (ODC);
- Identify and evaluate services to ensure that all systems, public and private, which are responsible for protecting or providing services to DW or the District's population with mental retardation or a developmental disability or ODC are accountable;
- Develop and monitor plans for the implementation of recommendations for systemic changes within the various governmental and private agencies and/or programs interfacing with DW or residents with mental retardation, developmental disability, or ODC; and
- Develop and monitor plans for implementation of recommendations to improve and maximize systemic responses to incidents of abuse, neglect and maltreatment. This shall include proposing amendments to statutes, policies and procedures, modifications to relevant service delivery training, and coordination of services to reduce any form of maltreatment.

*Some of the deaths reviewed were of individuals who resided in their natural home or outside of the District of Columbia.

Demographic Characteristics of Deceased Persons with MRDD

The total number of persons with MRDD served by MRDDA in the District of Columbia for the calendar years 2001, 2002 and 2003 were 1547, 1703 and 1790 respectively.

Table 1 presents the number of deaths from the population with MRDD reviewed by FRC.

Table 1 District of Columbia MRDDA Population* and Number of Deaths by Year

Year	Population	Number of Deaths	Percentage
2001	1547	32	2%
2002	1703	26	1.5%
2003	1790	31	1.7%

*Information on the total population for each of the three years was provided by MRDDA.

Results presented in Table 1 indicate that between 1.5 to 2 percent of the MRDD population died during the three-year period.

Age

Figure 1 presents information on the number of deaths by age groups for the three-year period.

Figure 1 Number of Deaths by Age Range

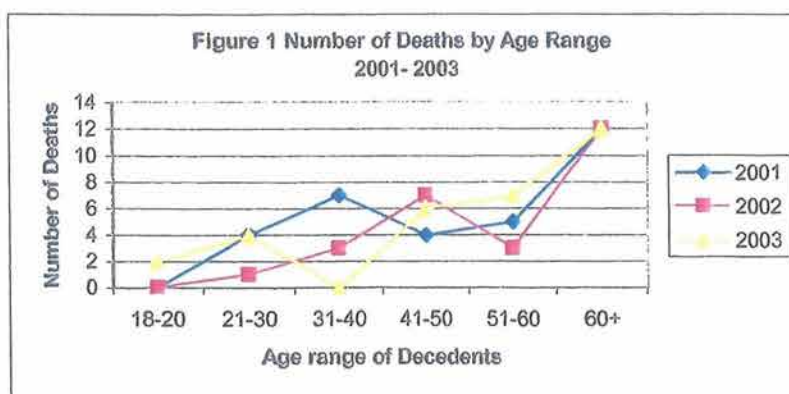


Table 2 illustrates the percentage of deaths reviewed by gender and age range for each year.

Table 2 Deaths by Age Range by Gender

Age Range	2001 N=32		2002 N=26		2003 N=31	
	Male	Female	Male	Female	Male	Female
18-20	0	0	0	0	3.2%	3.2%
21-30	6.2%	6.2%	3.8%	0	6.4%	6.4%
31-40	12.5%	9.4%	11.5%	0	0	0
41-50	3%	9.4%	11.5%	15.3%	9.6%	6.4%
51-60	9.4%	6.2%	7.6%	3.8%	16.1%	9.6%
61 and over	15.6%	22%	34.6%	11.5%	16.1%	22.5%

The FRC reviewed the deaths of persons with MRDD who ranged in age from 18 to 83. The information provided in Figure 1 and Table 2 indicate that the largest number of deaths were of persons 60 years of age and older (n=36). There were 16 deaths in age range 51-60, 16 deaths for ages 41-50, 10 deaths for ages 31-40, 9 deaths for ages 21-30 and 2 deaths for individuals 18-20 years of age.

Gender

Table 3 presents information on the gender of the persons whose deaths were reviewed by the FRC for the three-year period.

Table 3. Deaths by Gender for the three-year period (N=89)

Year	Gender				
	Males		Females		Total N=89
	Number of Deaths	Percentage	Number of Deaths	Percentage	
2001	15	47%	17	53%	32
2002	18	69%	8	31%	26
2003	16	52%	15	48%	31

The results presented in Table 3 indicate that there were approximately an equal number of males and females whose deaths were reviewed by the FRC during 2001 and 2003. During 2002, there was a larger percentage of males than females among the deceased group.

Race

Table 4 presents information on the MRDD population and deaths reviewed by race.

Table 4 Race of MRDD Population and Fatalities Reviewed by Year

Race	2001		2002		2003	
	Population N=1547	Deaths N=32	Population N=1703	Deaths N=26	Population N=1790	Deaths N=31
Black	1163	24	1411	17	1467	23
Caucasian	224	8	218	9	200	8
Other	160	0	64	0	123	0

The results presented in Table 4 indicated that deaths by race were consistent with the overall MRDD population.

Place of Death

Place of death included hospitals, nursing homes, hospice, and specialized home care, i.e., foster homes and other types of residential placement. Table 5 presents the place of death for the 89 individuals whose cases were reviewed during the three-year period.

Table 5 Place of Death

Place of Death	2001 N=32	2002 N=26	2003 N=31
Hospital	22	16	25
Nursing Home	6	6	5
Hospice	0	2	1
Residential	4	0	0
Other, e.g., specialized home care and foster homes	0	2	0

The information in Table 5 indicates that during the review period, almost all MRDD individuals died in hospitals (70%), and nursing homes (19%).

Residence at Time of Death

Residence at time of death refers to the individual's residential address by ward. Address includes natural homes, specialized home care, group homes, independent living facilities, supervised apartments and nursing homes. Residence at time of death by ward is presented in Table 6.

Table 6 Ward of Residence at Time of Death

District Wards	Decedents All Years N=89
One	8
Two	3
Three	3
Four	13
Five	7
Six	4
Seven	21
Eight	8
Maryland	19
Other States	3
Unknown Ward	3

The number of deaths reviewed by residence at the time of death was consistent with the MRDD population in those communities.

Cause and Manner of Death

Pursuant to Public Law 1435 for calendar years 2001, 2002 and 2003; and Mayor's Order 2004-76, "Autopsies of Deceased Clients of the Mental Retardation and Developmental Disability Administration", of May 13, 2004, an autopsy must be performed on all persons with MRDD who die in the District of Columbia and receive services and support from the Mental Retardation and Developmental Disability Administration.

Of the 89 cases reviewed, 83 individuals were autopsied during this review period. They presented with a wide variety of neurologic conditions including genetic defects; developmental malformations or diseases; sequellae of prenatal or perinatal brain insults, infectious diseases, degenerative brain diseases; and complications of atherosclerotic cardiovascular disease. In one case the symptoms resulted from head trauma. See Table 7.

Table 7 Primary Neurologic Conditions

Primary Neurologic Disorder	Consumers Affected
Mental Retardation, not otherwise specified	38
Hypoxic Encephalopathy/Cerebral palsy	19
Down's Syndrome	7
Alzheimer's disease	5
Porencephaly	3
Microcephaly	2
Cri du Chat Syndrome	2
Schizophrenia	2
Atherosclerotic Cerebrovascular Disease	2
Complications of Leptomeningitis	1
Klippel-Feil Syndrome	1
Seizure Disorder/Brain trauma	1
Head Trauma	1

Cause of Death

Cause of death is defined as the natural underlying pathological condition or injury that initiates the chain of events which will bring about the demise. The majority of the deaths in the MRDD population for calendar years 2001 through 2003 were due to medical conditions as listed in Table 8 below.

Table 8. Cause of Death

Cause of Death	Number of Deaths
Neurologic Diseases	28
Cardiovascular Diseases (Hypertension, Atherosclerosis)	24
Cancer	9
Gastrointestinal Diseases	9
AIDS	2
Sepsis	2
Hemoglobinopathy	2
Chronic Obstruction Pulmonary Disease	2
Trauma	2
Diabetes Mellitus	1
Fluvoxamine Intoxication	1

The neurologic disorder which placed these individuals in this special category was the underlying cause of death in twenty-eight (28) cases. In the remaining population, cardiovascular diseases were the most prevalent causes of death, twenty-four (24) cases, followed by neoplasms, nine (9) cases, and gastrointestinal disorders, nine (9) cases.

Pneumonia/Bronchopneumonia was the most frequent terminal cause of death in twenty-two (22) cases, complicating both neurologic and cardiovascular diseases. Pulmonary thromboembolism and infections secondary to impaired mobility contributed to six (6) deaths, and therapy related measures were associated with three (3) deaths.

Six of the 89 cases reviewed died out-of-state and their causes and manner of death are not available at this time.

Consultation with Dr. Steven S. Wolf, MD, Director of Neurology Services, Saint Elizabeths Hospital, DC Department of Mental Health, supports that respiratory ailments are the most prevalent causes of death in "patients" with neurologic disorders. According to Dr. Wolf, persons with MRDD are at heightened risk for developing aspiration pneumonia. Moreover, because of impairment in their ability to communicate or manifest their symptoms, they may not come to medical attention as quickly as one might hope, despite being under the supervision of caregivers. See Appendix E.

The two leading non-neurologic causes of death in the MRDD population closely match the national population as reported by the Centers for Disease Control¹

¹ Center for Disease Control, National Vital Statistics Report, Deaths: Preliminary Data for 2002, p3.

Manner of Death

The manner of death refers to the circumstantial events surrounding the death. The manner of death, as determined by the forensic pathologist, is an opinion based on the known facts concerning the circumstances leading up to and surrounding the death, in conjunction with the findings at autopsy and the laboratory tests.²

Of the 89 deaths reviewed during 2001-2003, the manner of death was determined as natural for seventy-nine individuals. Six deaths were determined to have been accidental. Of these, 3 cases were related to traffic accidents, 1 case was due to a fall, and 2 cases were due to choking on solid food. In one case, manner of death was undetermined. Information on three cases was unavailable pending out-of-state requests for death information.

² V.L.D. DiMais Forensic Pathology 2nd Edition, 2001

Highlights and a Look Forward

This report highlights the following:

- The death rate for persons with MRDD whose deaths were reviewed by the Fatality Review Committee was between 1.5 percent and 2 percent for the three year period;
- The majority of the deaths occurred in individuals who were sixty years of age or older;
- The deaths of persons with MRDD were overwhelmingly due to natural causes;
- The majority of deaths of persons with MRDD occurred in health care facilities such as hospitals, and nursing homes;
- FRC recommendations issued during the period emphasize the need for comprehensive policy development to support coordination of care for persons with MRDD who live in community residential facilities. See Appendix D

The Fatality Review Committee will continue to convene on a monthly basis to review cases and to formulate recommendations to address systemic issues.

Consistent with the Mayor's Order, the Advisory Panel will play a significant role in implementing recommendations suggested by the Fatality Review Committee.

Future goals and objectives of the Fatality Review Committee include monitoring previously issued recommendations and to develop a comprehensive approach to improve services District-wide for persons with MRDD.

As noted in the American Journal of Mental Retardation:

The real issue of mortality is how death relates to policy and program development by identifying the deficiencies in the quality of care and services for persons with mental retardation and other developmental disabilities and in how to correct these deficiencies and improve quality assurance in both settings.³

This initial report focused upon the causes of death, and the concomitant medical factors that contributed to deaths of the 89 individuals reviewed. Subsequently, the Fatality Review Committee in its review of diagnoses and causes of deaths in persons with MRDD will continue to incorporate policy and program development enhancements into its recommendations. Future reports will provide tracking and trending analysis and additional recommendations for systemic changes. These reports will also highlight, through recommendations presented, those trends that can effectuate improvements in the areas of coordination of care, case record documentation, end-of-life issues and other service delivery concerns for persons with MRDD who live in the District of Columbia.

³ "Mortality Among People with Mental Retardation Living in the United States: Research Review and Policy Application," by Mary F. Hayden: The American Association on Mental Retardation Journal of Mental Retardation, October 1998, p. 346.



Appendices

Mental Retardation Developmental Disabilities Review Committee

By virtue of the authority vested in me as Mayor of the District of Columbia pursuant to section 422(2) of the District of Columbia Home Rule Act of 1973, as amended, 87 Stat. 790. Pub. L.No.93-198, D.C. Code1-242(2)(1999 Repl.), it is hereby ORDERED that 2001-27:

I. ESTABLISHMENT

There is hereby established in the government of the District of Columbia the District of Columbia Mental Retardation and Developmental Disabilities Administration Fatality Review Committee (herein referred to as the Committee)

II. PURPOSE

The District of Columbia MRDDA Fatality Review Committee shall examine events and circumstances surrounding the deaths of District wards or residents in the District with mental retardation, developmental disability or other disabling condition (ODC) in an effort to reduce the number of preventable deaths; assist the District in gaining Empirical evidence into fatalities occurring within the community; Provide a mechanism for the District government and community to become actively involved in reducing the factors that negatively impact the health, safety and welfare of the target population; and promote improved and integrated public and private systems serving District residents.

III. Duties

- A. Expeditionously review deaths of residents living in group homes, foster homes, nursing homes or any other health care entity licensed by and located in the District of Columbia;
- B. Identify the causes and circumstances contributing to deaths of District wards (DW) or residents with mental retardation, developmental disability or ODC;
- C. Identify and evaluate services to ensure that all systems, public and private, which are responsible for protecting or providing services to DW or the District's population with mental retardation or a developmental disability or ODC are accountable;
- D. Develop and monitor plans for the implementation of recommendations for systemic changes within the various governmental and private agencies and/or programs interfacing with DW or residents with mental retardation, developmental disability, or ODC; and
- E. Develop and monitor plans for implementation of recommendations to improve and maximize systemic responses to incidents of abuse, neglect and maltreatment. This shall include proposing amendments to statutes, policies and procedures, modifications to relevant service delivery training, and coordination of services to reduce any form of maltreatment.

IV FUNCTIONS

The Committee shall:

- A. Within ninety (90) days of the date of this Order, develop and issue procedures governing its overall operation and the activities and operations of the Fatality Review Teams. The procedures shall include, at a minimum, the following:
1. The composition and method of operating the review teams;
 2. Methods by which deaths of DW or residents with mental retardation, developmental disability or ODC are identified to ensure expeditious and quality reviews;
 3. A method for ensuring that all information identifying DW or residents with mental retardation, developmental disability, or ODC, and their families and others associated with the case or the circumstances surrounding a serious incident or death, including witnesses and complainants, is protected from disclosure;
 4. A process for governing the protection of each individual's privacy, confidentiality and the dissemination of information and case records;
 5. A process by which serious incident or fatality cases are screened and selected for review, and the type of level of review required is determined.
 6. A systematic method for gathering individual and cumulative data from the reviews.
 7. A method for ensuring that information required for the review is immediately made available for use by the Fatality Review Teams;
 8. A methods of implementing recommendations generated by the Committee and addressing problems related to obstacles/barriers to implementation, and
 9. A method for evaluating the work of the Committee community responses to the deaths of DW or residents with mental retardation, developmental disability, or ODC.
- B. Promulgate recommendations based on the findings of the reviews that support the development and implementation of new or revised services, practices, policies and procedures of agencies and programs (public and private) and that will further the protection of the target population, and
- C. By 30 April of each year, an annual report shall be produced by the Committee Coordinator that provides information and statistical data obtained from the reviews that were conducted during the previous calendar year. The annual report shall be submitted to the Mayor and made available to the public. The information contained in the report shall include, at a minimum:
1. Statistical data on all fatalities of DW or residents with mental retardation or a developmental disability, or ODC, including cause and manner of death, and socio-demographic data;
 2. Analyses of the data generated by the reviews to demonstrate the types of cases reviewed (which may include illustrative case vignettes without identifiers), similarities or patterns of factors causing or contributing to the deaths, and trends (both temporal and geographic); and
 3. Recommendations that are generated from the reviews, including service expansion; systemic improvements or reforms; and required changes in laws, policies/procedures and practices that could further the protections of DW or residents with mental retardation, developmental disability, or ODC from preventable causes of death, and

V. COMPOSITION OF THE FATALITY REVIEW COMMITTEE

The members, as designated hereunder, shall be appointed by the Mayor based on individual expertise in relevant disciplines and their familiarity with the laws, standards and services related to the protection of the health and welfare of DW or residents with mental retardation, developmental disability, or ODC in the District of Columbia.

- A. Eight (8) public members from the community who are not employees of the Government of the District of Columbia. All efforts shall be made to ensure proportionate representation from each ward of the District;
- B. Two (2) faculty members from Schools of Social Work from colleges/Universities in the District of Columbia;
- C. Two (2) physicians who practice in the District of Columbia with experience in the evaluation and treatment of mentally retarded, developmentally disabled or ODC persons;
- D. Ex officio members shall include the department head or designee thereof from following agencies/institutions/committees or its successor programs:
 - 1. Department of Human Services (DHS):
 - a. Mental Retardation and Developmental Disabilities Administration (MRDDA)
 - b. Adult Protective Services (APS)
 - c. Rehabilitative Services Administration (RSA)
 - d. Office of Inspections and Compliance (OIC)
 - 2. Office of the Chief Medical Examiners (OCME)
 - 3. Department of Health (DOH)
 - a. Medical Assistance Administration (MAA)
 - b. State Center for Health Statistics (SCHS)
 - c. Health Regulation Administration (HRA)
 - d. Bureau of Injury and Disability Prevention (BIDP)
 - 4. Metropolitan Police Department, Criminal Investigations Division (MPD)
 - 5. Office of the Corporation Counsel (OCC) [Office of the Attorney General]
 - 6. Office of the Inspector General (OIG)
 - 7. Commission [Department] on Mental Health (DMH)
 - 8. Fire Department & Emergency Medical Services, EMS Director
- E. The following agencies may be included, should they agree to participate:
 - 1. Office of the United States Attorney for the District of Columbia
 - 2. Superior Court of the District of Columbia

The Chief Medical Examiner for the District and a social service professional who practices and/or teaches in the District with experience in the evaluation and provision of services to persons with mental retardation or developmental disability shall be appointed by the Mayor as Co-Chairpersons and shall serve at the pleasure of the Mayor.

VI. TERMS

Public members of the Committee shall serve for 3-year terms except that, of the members first appointed under the Order, one-third shall be appointed for 3-year terms, one-third for 2-year terms and one-third for a 1-year term. The date the first members are installed shall become the anniversary date for all subsequent appointments.

- A. An appointed member to fill an unexpired term shall serve for the remainder of that term. Members may continue to serve until reappointed or replaced. Members may serve not more than two consecutive terms;
- B. Each representative, and review team member representing a specific public or private agency, shall be designated by his or her respective institutional head and shall serve at the pleasure of the Mayor, and
- C. Ex officio voting and non-voting members shall serve at the pleasure of the Mayor.

VII. COMMITTEE COORDINATOR: ROLES AND RESPONSIBILITIES

The Committee Coordinator shall serve as the focal point for receiving case notification and information, as well as for the appropriate dissemination of information to the Committee. Some of the responsibilities of the Coordinator, under the director of the committee Co-Chairs and with the assistance of Committee members, shall include:

- A. Receive and log in all reports and fatalities;
- B. Determine the type of case and review required;
- C. Monitor each case to ensure that reviews are held in a timely manner and report due dates are met;
- D. Gather, review and analyze data and information to plan reviews;
- E. Interview the court monitor for the Pratt (Evans) class members, to assure input from the monitor into the review process;
- F. Develop a summary for the Committee file;
- G. Develop and manage case identification system which ensures confidentiality and anonymity of cases except as required by protocols;
- h. Collect and distribute case data while preserving confidentiality;
- i. Schedule and facilitate meeting of the Full Committee and Advisory Panel;
- j. Notify appropriate Committee members and non-Committee members in a timely manner of fatality case review meetings;
- k. At the conclusion of each review, retrieve materials and file necessary data in secure location;
- l. Manage information system (data collection, entry and analysis);
- m. Develop final report for each case reviewed and manage dissemination of reports;
- n. Facilitate communication among participating agencies;
- o. Assist in the preparation of the Annual Report; and
- p. Serves as the Committee liaison to other fatality review committees.

VIII. AGENCY LIAISONS: ROLES AND RESPONSIBILITIES

Each agency/program shall designate a Community Liaison to work directly with the Coordinator. This person shall serve as the primary point of contact for the agency, and shall be responsible for facilitating the process of providing information from that agency for the review process. Some of the duties of the Liaisons shall include:

- A. Provide timely and proper notification to the Committee of fatalities of DW's.
- B. Search the records of the Agency;
- C. Provide requested documents, data and information to the Coordinator (which may include results of internal reviews);
- D. Prepare the agency Committee member(s) for meetings of the Committee or Advisory Board; and
- E. Provide follow-up information to the Coordinator as requested

IX. TEAM STRUCTURES

The Committee shall convene as the full Committee and as an Advisory Panel.

A. Full Committee

1. A minimum of two-thirds of the members shall be present to constitute a quorum. Meetings of the full Committee will be for the purpose of:
 - a. Conducting case reviews, or assessing additional data from prior cases that have since become available;
 - b. Consideration of recommendations arising from available case reviews;
 - c. Preparation of the annual report;
 - d. Any other business necessary for the Committee to operate or fulfill its duties.
2. Case review meetings of the full Committee shall be held monthly, if there are cases for review. After procedures have been established, reviewed and tested the Committee may consider holding case review meetings bimonthly, if practicable.). The full Committee may also convene monthly or ad hoc meetings as needed for additional case reviews, or for other specific purposes of the committee, e.g., development of recommendations, preparation of the Annual Report.
3. The Committee shall conduct multi-disciplinary reviews of the events and circumstances surrounding the deaths of DW's as defined in Section II, in order to provide the data to fulfill the Purposes and Duties of the Committee as enumerated in Sections II and III, respectively.
4. Case reviews will occur at the next Committee meeting after the Committee receives notification of the fatality, or at the first meeting after sufficient materials are received for conducting the review. If the death is criminal in nature or under active criminal investigation, the review shall be preliminary, pending conclusion of the investigation and prosecution, or release by the prosecutor to conduct the review, at which time a comprehensive shall be conducted.

5. The case review process shall include a presentation of the case summary, followed by presentations of relevant information concerning the death by any agencies or person involved with the DW, or investigating the event.
6. Following presentation of the facts, the Committee will discuss the case and any issues that it raises, guided by the following principles and questions:
 - a. What factors or circumstances caused or contributed to the death? (This may include consideration of systemic concerns related to the community, service and medical care providers, government supervision and regulation, and applicable or needed laws, procedures and regulations.).
 - b. What responses and investigations resulted from the death? (This involves whether all necessary agencies were notified and responded, and whether any corrective actions were instituted.
 - c. Were the services, interventions and investigations concerning the DW appropriate and adequate for his/her needs? (In other words, did the systems and agencies provide and plan effectively for the DW?)
 - d. Were the staff involved with the DW adequately prepared, trained and supported to perform their duties correctly?
 - e. Was there adequate communication and coordination among the various entities involved with the DW?
 - f. Are the applicable statutes, regulations, policies and procedures adequate to serve the needs of the target population? If not, what changes to them are needed?
7. Based on the case discussion, the Committee shall formulate applicable recommendations as enumerated above in Sections IIID and IV B and C (3), for further consideration and possible inclusion in the Annual Report.

B. Advisory Panel

1. An Advisory Panel shall be established for the purposes of addressing interagency and intergovernmental issues, especially those that concern coordination of service delivery to DW's, and implementing recommendations made by the Committee. This panel will be responsible for advising the Mayor direction, developing implementation of strategies for the recommendations. The Advisory Panel shall also monitor the response to and implementation of the recommendations, address problems or obstacles to implementation, and report this to the full Committee.
2. The Advisory Panel shall meet semi-annually. The Advisory Panel may convene ad hoc meetings of its own volition, or at the request of the Committee or the Mayor, whenever necessary to fulfill its duties.
2. The Advisory Panel shall comprise the directors of relevant District Departments, who shall serve as ex officio. The Advisory Panel shall, at a minimum, include the following agencies:
 - (a) Department of Human Services (DHS)
 - (b) Office of the Chief Medical Examiner (OCME)
 - (c) Department of Health (DOH)

- (d) Office of the Corporation Counsel (OCC)
- (e) Metropolitan Police Department (MPD)
- (f) Office of the Inspector General (OIG)

- 4. The Panel may also include the following agencies, should they agree to participate:
 - (a) Office of the US Attorney for the District of Columbia
 - (b) District of Columbia Superior Court.

X CASE REVIEW CRITERIA AND PROCEDURES

- A. All deaths of DWs older than 18 years of age will be reviewed by the Committee. (Note: Deaths of DWs who are 18 years of age or less will be reviewed by the Child Fatality Review Committee.)
- B. Factors of particular concern for review include:

1. All violent or unexpected manners of death (I.e.g, homicide, suicide, accident, underdetermined), which include all deaths caused by injuries, including but not limited to:

- (a) blunt trauma, including fractures
- (b) burns
- (c) asphyxia or drowning
- (d) poisoning or intoxication
- (e) gunshot wounds
- (f) Abuse, either physical or sexual
- (g) Neglect, including medical and custodial
- (h) Malnourishment or dehydration
- (l) Circumstance or events deemed suspicious

- C. The Committee may, at its discretion, review groups of sudden, unexpected or unexplained deaths of DWs to examine aggregate data in order to address specific issues or trends.
- D. DWs who live in facilities outside the District, or who die outside the District, will be subject to review by the Committee, and will be included in the Annual Report, both for statistical analysis and recommendations. The Committee members shall serve as liaisons to their counter parts in outside jurisdictions for the purpose of gathering information and obtaining documents (e.g., police or autopsy reports) to complete the review.

XI. CASE NOTIFICATION PROCEDURES

- A. District agencies and service providers contracted by the District to serve DWs shall provide written notification to the Committee within 24 hours of any death of a DW, or within 24 hours of becoming aware of such a death. The sources of case notifications will include but not limited to:
 - 1. MRDDA
 - 2. Contracted service providers (e.g., group home staff)
 - 3. OIC

4. OCME
5. MPD
6. OIG
7. OCC
8. DOM

Case notifications may be made by any other person or entity with knowledge of a death of a DW.

- B. Case notification reports should include for the affected DW:
1. Demographic data (name, age/date of birth, race, gender)
 2. Address
 3. Parents/guardians
 4. Circumstances of the death (date, time, location, activities or risk factors, witnesses or sources of information.)
 5. Agencies investigating the death
 6. History of involvement of government agencies or contracted service providers.
- C. MPD, DHS (OIC and MRDDA), DOH and OIG shall provide the Committee with copies of all death reports resulting from any investigation that is conducted on DWs. OCME shall provide the Committee with copies of all autopsy reports resulting from autopsies and death investigations conducted on DWs. These reports shall be provided within five (5) days after they are completed.

XII. NOTIFICATION OF PARTICIPANTS

Notification shall be provided in writing to all review participants two (2) weeks prior to the review. Notification shall include sufficient information for the case to be researched, the record identified and reviewed and adequate information related to the nature of the agency's involvement collected for presentation during the review meeting. Any agreed upon information shall be provided to the Committed Coordinator prior to the review. Prior to the review meeting, these may include experts from various relevant disciplines or service areas.

XIII. RECORDS

All records and reports shall be maintained in a secured area with locked file cabinets. Three (3) years after the Annual Report has been distributed, all supporting documentation in each fatality record shall be destroyed. The only material that will be maintained in a fatality record will include the following:

- B. Final Report; and
- C. Death Certificate

XIV. CONFIDENTIALITY

A. A key tenet of the Committee is the necessity for keeping confidential all information obtained by, presented to and considered by the Committee. Any information gathered in preparation for or divulged during Committee reviews may not be disclosed for purposes other than those outlined in this Mayor's Order. All participants in the Committee proceedings shall be required to sign a confidentiality statement during all Committee case review meetings and in general meetings where any specific case is discussed. Case specific information distributed during the meeting shall be collected at the end of each review. Any required participant who is not willing to sign a confidentiality statement or abide by the confidentiality requirements shall not be allowed to participate in case review meetings.

B. Confidentiality Protocols

Methods for ensuring that all information identifying DWs and their families is protected against disclosure are:

1. The Committee Coordinator shall be designated as the individual responsible for receiving and protecting all records.
2. During the notification and case selection process, every case will be assigned a number identifier and a record established. The full name of the DW and family shall be maintained in the case records at all times during the review planning process.
3. All case records shall be maintained in a locked file cabinet at all times unless in use by the Committee Coordinator or other designated staff of the Committee
4. All records from other agencies/programs shall be obtained by or delivered directly to the committee Coordinator. Once the necessary documents from the various member agencies/programs related to service delivery or interventions provided to the DW are received, they shall be maintained in the case record only.
5. A case summary shall be prepared for each case and stapled to the left side cover of the file folder, for use by the Coordinator and chair of the review meeting.
6. No further duplication of documents is permitted.
7. Any documents distributed during the review shall only identify the DW by the Committee case number identifier.
8. Upon completion of the review of a case, all documents/information distributed shall be returned to the Committee Coordinator or other designated Committee Staff. One (1) copy shall be maintained in the case record, along with a copy of the list of review participants, confidentiality statements for each review participant and the agenda. The remaining copies of the information distributed shall be shredded immediately after the review.
9. The final report from each review, describing the discussion, analysis of issues and recommendations, shall be prepared and included in the case record, which must be maintained in a secured file cabinet. These report are not public documents and shall be maintained only in the Committee record. Persons where were involved with the family may review only the final report. Review may only occur in the Committee office and copying or faxing of these documents is not permitted.

10. All information contained in the Committee record identifying the DW, his/her family and any party or agency involved with the family at the time of or prior to the death shall be destroyed three (3) years after the Annual Report has been issued.
 11. Committee and Review Team members shall not disclose any case-specific information about the death (including the surrounding circumstances) derived from the review process to the press or any other third party.
 12. The Committee Annual Report represents the only public document for distribution by the Committee. These Reports shall not contain any identifying information related to the DWs or their families.
- C. Methods of ensuring that all information identifying third persons such as witnesses, complainants and agency/institution/program staff or professional involved with the family are protected against disclosure are:
1. The same procedures established for DW's and their families above shall be followed for these entities.
 2. Access to primary documents will be limited to the staff of the Committee and the chair of the review meeting.
 3. Initials only will identify their persons in materials for distribution.

XV: RECOMMENDATIONS

- A. Draft recommendations shall be developed by the Committee Coordinator based on issues raised during the review.
- B. Draft recommendations shall be distributed to Departments and members for review and comment. Recommendations are finalized based on the comments received, including discussion at meeting of the Full Committee.
- C. Final recommendations are incorporated in the Annual Report, and are forwarded to the Mayor. interim recommendations may be forwarded to the affected entities for expeditious implementation, at the approval of the Mayor or his/her designee.
- D. Representatives from agencies, institutions and programs may be invited to Full Committee meetings to present their plans for or progress made towards implementation of recommendations.
- E. The Advisory Panel will address interagency and intergovernmental issues related to implementation of recommendations, and will advise the Mayor or his/her designee regarding such concerns.

XVI. COMPENSATION

Committee members shall serve without compensation.

XVII. ADMINISTRATION

Appropriate administrative support, facilities and resources to ensure the effective operation of the Committee and the implementation of the requirements of The Mayor's Order establishing this committee shall be provided under the direction of the Chief Medical

Examiner. Expenses shall be obligated against funds designated for the purpose by the Department of Human Services or the Executive Office of the Mayor.

All agencies of the District of Columbia government that were involved with the DW shall cooperate with the Committee and provide timely access to information necessary to carry out its duties, subject to the applicable District and Federal statutes and regulations governing privacy, dissemination and confidentiality of information.

XVIII. EFFECTIVE DATE

This Order shall become effective immediately.

LEXSTAT DC CODE 7-1301.03

LEXIS DISTRICT OF COLUMBIA CODE ANNOTATED
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*** CURRENT THRU ACT 15-441; 51 DCR 6524, JUNE 25, 2004 ***
*** ANNOTATIONS CURRENT THRU JUNE 17, 2004 ***

TITLE 7. HUMAN HEALTH CARE AND SAFETY
SUBTITLE D. MENTALLY RETARDED CITIZENS
CHAPTER 13. RIGHTS OF MENTALLY RETARDED CITIZENS
SUBCHAPTER I. STATEMENT OF PURPOSE; DEFINITIONS

GO TO CODE ARCHIVE DIRECTORY FOR THIS JURISDICTION

D.C. Code § 7-1301.03 (2004)

§ 7-1301.03. Definitions [Formerly § 6-1902]

As used in this chapter:

(1) "Admission" means the voluntary entrance by an individual who is at least moderately mentally retarded into an institution or residential facility.

(2) "At least moderately mentally retarded" means a person who is found, following a comprehensive evaluation, to be impaired in adaptive behavior to a moderate, severe or profound degree and functioning at the moderate, severe or profound intellectual level in accordance with standard measurements as recorded in the Manual of Terminology and Classification in Mental Retardation, 1973, American Association on Mental Deficiency.

(2A) "Cause injury to others as a result of the individual's mental retardation" means cause injury to others as a result of deficits in adaptive functioning associated with mental retardation.

(3) "Chief Program Director" means an individual with special training and experience in the diagnosis and habilitation of mentally retarded persons, and who is a Qualified Mental Retardation Professional appointed or designated by the Director of a facility for mentally retarded persons to provide or supervise habilitation and care for customers of the facility.

(4) "Commitment" means the placement in a facility, pursuant to a court order, of an individual who is at least moderately mentally retarded at the request of the individual's parent or guardian without the consent of the individual or of an individual found incompetent in a criminal case at the request of the District; except it shall not include placement for respite care.

(5) "Community-based services" means non-residential specialized or generic services for the evaluation, care and habilitation of mentally retarded persons, in a community setting, directed toward the intellectual, social, personal, physical, emotional or economic development of a mentally retarded person. Such services shall include, but not be limited to, diagnosis, evaluation, treatment, day care, training, education, sheltered employment, recreation, counseling of the mentally retarded person and his or her family, protective and other social and socio-legal services, information and referral, and transportation to assure delivery of services to persons of all ages who are mentally retarded.

(5A) "Competent" means to have the mental capacity to appreciate the nature and implications of a decision to enter a facility, choose between or among alternatives presented, and communicate the choice in an unambiguous manner.

(6) "Comprehensive evaluation" means an assessment of a person with mental retardation by persons with special training and experience in the diagnosis and habilitation of persons with mental retardation, which includes a sequence of observations and examinations intended to determine the person's strengths, developmental needs, and need for services. The initial comprehensive evaluation shall include, but not be limited to, a physical examination that includes the person's medical history; an educational evaluation, vocational evaluation, or both; a psychological evaluation, including an evaluation of cognitive and adaptive functioning levels; a social evaluation; and a dental examination.

(7) "Council" means the Council of the District of Columbia.

(8) "Court" means the Superior Court of the District of Columbia.

(8A) "Crime of violence" has the same meaning as in § 23-1331(4).

(8B) "Customer" means a person admitted to or committed to a facility pursuant to subchapter III of this chapter for habilitation or care.

(9) "Department of Human Services" means the Department of Human Services of the District of Columbia.

(10) "Director" means the administrative head of a facility, or community-based service and includes superintendents.

(11) "District" means the District of Columbia government.

(11A) "DSM-IV" means the most recent version of the Diagnostic and Statistical Manual of Mental Disorders.

(11B) "DSM-IV "V" Codes" means "V" codes as defined in the most recent version of the Diagnostic and Statistical Manual of Mental Disorders.

(12) "Education" means a systematic process of training, instruction and habilitation to facilitate the intellectual, physical, social and emotional development of a mentally retarded person.

(13) "Facility" means a public or private residence, or part thereof, which is licensed by the District as a skilled or intermediate care facility or a community residential facility (as defined in D.C. Regulation 74-15, as amended) and also includes any supervised group residence for mentally retarded persons under 18 years of age. For persons committed or for whom commitment may be sought under § 7-1304.06a, the term "facility" may include a physically secure facility or a staff-

secure facility, within or without the District of Columbia. The term "facility" does not include a jail, prison, other place of confinement for persons who are awaiting trial or who have been found guilty of a criminal offense, or a hospital for the mentally ill within the meaning of § 24-501.

(14) "Habilitation" means the process by which a person is assisted to acquire and maintain those life skills which enable him or her to cope more effectively with the demands of his or her own person and of his or her own environment, including, in the case of a person committed under § 7-1304.06a, to refrain from committing crimes of violence or sex offenses, and to raise the level of his or her physical, intellectual, social, emotional and economic efficiency. "Habilitation" includes, but is not limited to, the provision of community-based services.

(14A) "ICD-9-CM" means the most recent version of the International Classification of Diseases Code Manual.

(14B) "Individual found incompetent in a criminal case" means an individual who:

- (A) Is at least mildly mentally retarded;
- (B) Is charged with a crime of violence or sex offense;
- (C) Has been found incompetent to stand trial, or to participate in sentencing or transfer proceedings; and
- (D) Has been found not likely to gain competence in the foreseeable future.

(15) "Informed consent" means consent voluntarily given in writing with sufficient knowledge and comprehension of the subject matter involved to enable the person giving consent to make an understanding and enlightened decision, without any element of force, fraud, deceit, duress or other form of constraint or coercion.

(16) "Least restrictive alternative" means that living and/or habilitation arrangement which least inhibits an individual's independence and right to liberty. It shall include, but not be limited to, arrangements which move an individual from:

- (A) More to less structured living;
 - (B) Larger to smaller facilities;
 - (C) Larger to smaller living units;
 - (D) Group to individual residences;
 - (E) Segregated from the community to integrated with community living and programming;
- and/or
- (F) Dependent to independent living.

(17) "Mayor" means the Mayor of the District of Columbia.

(17A) "Mental illness" means a diagnosable mental, behavioral, or emotional disorder (including those of biological etiology) which substantially impairs the mental health of the person or is of sufficient duration to meet diagnostic criteria specified within the DSM-IV or its ICD-9-CM equivalent (and subsequent revisions) with the exception of DSM-IV "V" codes, substance abuse disorders, mental retardation, and other developmental disorders, or seizure disorders, unless those exceptions co-occur with another diagnosable mental illness.

(18) "Mental retardation advocate" means a member of the group of advocates created pursuant to § 7-1304.13.

(19) "Mental retardation" or "mentally retarded" means a substantial limitation in capacity that manifests before 18 years of age and is characterized by significantly subaverage intellectual functioning, existing concurrently with 2 or more significant limitations in adaptive functioning.

(19A) "MRDDA" means the Mental Retardation and Developmental Disabilities Administration of the District of Columbia, Department of Human Services.

(20) "Normalization principle" means the principle of aiding mentally retarded persons to obtain a lifestyle as close to normal as possible, making available to them patterns and conditions of everyday life which are as close as possible to the patterns of mainstream society.

(21) "Qualified mental retardation professional" means:

(A) A psychologist with at least a master's degree from an accredited program and with specialized training or 1 year of experience in mental retardation; or

(B) A physician licensed by the Commission on Licensure to Practice the Healing Arts to practice medicine in the District and with specialized training in mental retardation or with 1 year of experience in treating the mentally retarded; or

(C) An educator with a degree in education from an accredited program and with specialized training or 1 year of experience in working with mentally retarded persons; or

(D) A social worker with:

(i) A master's degree from a school of social work accredited by the Council on Social Work Education (New York, New York), and with specialized training in mental retardation or with 1 year of experience in working with mentally retarded persons; or

(ii) With a bachelor's degree from an undergraduate social work program accredited by the Council on Social Work Education who is currently working and continues to work under the supervision of a social worker as defined in sub-subparagraph (i) of this subparagraph, and who has specialized training in mental retardation or 1 year of experience in working with mentally retarded persons; or

(E) A rehabilitation counselor who is certified by the Commission on Rehabilitation Counselor Certification (Chicago, Illinois) and who has specialized training in mental retardation or 1 year of experience in working with mentally retarded persons; or

(F) A physical or occupational therapist with a bachelor's degree from an accredited program in physical or occupational therapy and who has specialized training or 1 year of experience in working with mentally retarded persons; or

(G) A therapeutic recreation specialist who is a graduate of an accredited program and who has specialized training or 1 year of experience in working with mentally retarded persons.

(22) "Resident of the District of Columbia" means a person who maintains his or her principal place of abode in the District of Columbia, including a person with mental retardation who would be a resident of the District of Columbia if the person had not been placed in an out-of-state facility by the District. A person with mental retardation who is under 21 years of age shall be deemed to be

a resident of the District of Columbia if the custodial parent of the person with mental retardation is a resident of the District of Columbia.

(23) "Respite care" means temporary overnight care provided to a mentally retarded person in a hospital or facility, upon application of a parent, guardian or family member, for the temporary relief of such parent, guardian or family member, who normally provides for the care of the person.

(24) "Respondent" means the person whose commitment or continued commitment is being sought in any proceeding under this chapter.

(24A) "Screening" means an assessment of a person with mental retardation in accordance with standards issued by the Accreditation Council for Services for People with Developmental Disabilities, which is designed to determine if a further evaluation of the person with mental retardation or other interventions are indicated.

(24B) "Sex offenses" means offenses in § 22-3001 et seq., but does not include any offense described in § 22-4016(b).

(25) "Time out" means time out from positive reinforcement, a behavior modification procedure in which, contingent upon undesired behavior, the resident is removed from the situation in which positive reinforcement is available.

(26) "Transfer proceedings" means the proceedings pursuant to § 16-2307 to transfer an individual less than 18 years of age from Family Court to Criminal Court in the Superior Court of the District of Columbia to face adult criminal charges.

HISTORY: 1973 Ed., § 6-1652; Mar. 3, 1979, D.C. Law 2-137, § 103, 25 DCR 5094; 1981 Ed., § 6-1902; Sept. 26, 1995, D.C. Law 11-52, § 506(b), 42 DCR 3684; Oct. 17, 2002, D.C. Law 14-199, § 2(a), 49 DCR 7647.

NOTES:

SECTION REFERENCES. --This section is referenced in § 7-1303.12a and § 16-2315.

EFFECT OF AMENDMENTS. --D.C. Law 14-199 added (2A); added "or of an individual found incompetent in a criminal case at the request of the District" in (4); inserted present (8A) and redesignated former (8A) as (8B); added (11A) and (11B); added the last two sentences in (13); inserted "including, in the case of a person committed under § 7-1304.06a, to refrain from committing crimes of violence or sex offenses" in (14); added (14A), (14B), and (17A); rewrote (19); and added (19A), (24B), and (26).

EMERGENCY ACT AMENDMENTS. --For temporary amendment of this section, see § 2(a) of the Civil Commitment of Citizens with Mental Retardation Emergency Amendment Act of 2002 (D.C. Act 13-383, June 12, 2002, 49 DCR 5701).

For temporary amendment of section, see § 2(a) of the Civil Commitment of Citizens with Mental Retardation Legislative Review Emergency Amendment Act of 2002 (D.C. Act 14-454, July 23, 2002, 49 DCR 8096).

LEGISLATIVE HISTORY OF LAW 2-137. --See note to § 7-1301.02.

LEGISLATIVE HISTORY OF LAW 10-253. --See note to § 7-1301.02.

LEGISLATIVE HISTORY OF LAW 11-52. --See note to § 7-1301.02.

LEGISLATIVE HISTORY OF LAW 14-199. --Law 14-199, the "Civil Commitment of Citizens with Mental Retardation Amendment Act of 2002," was introduced in Council and assigned Bill No. 14-616. The Bill was adopted on first and second readings on June 4, 2002 and July 2, 2002, respectively. Signed by the Mayor on July 17, 2002, it was assigned Act No. 14-432 and transmitted to Congress for its review. D.C. Law 14-199 became effective on October 17, 2002.

ANALYSIS

Construction

Guardian

CONSTRUCTION.

When construing D.C. Code 7-1301.03(1), as it applies to a person who is only mildly retarded, the inclusion of the words "at least moderately mentally retarded" in the definition of "admission" was an oversight by the City Council, and as such, voluntary admissions are available to mentally retarded persons regardless of their degree of retardation. *In re Bicksler, App. D.C., 501 A.2d 1 (1985).*

GUARDIAN.

The term "guardian", as used in the definition of respite care under D.C. Code § 7-1301.03(23), does not include a government entity such as the Department of Human Services, even if it acts as a provider of care to a mentally retarded person given the emphasis in the legislative history on maintaining family ties with a mentally retarded person. *In re Williams, App. D.C., 471 A.2d 263 (1984).*

GOVERNMENT OF THE DISTRICT OF COLUMBIA

ADMINISTRATIVE ISSUANCE SYSTEM

Mayor's Order 2004-76
May 13, 2004

SUBJECT: Autopsies of Deceased Clients of the Mental Retardation
And Developmental Disability Administration


ORIGINATING AGENCY: Office of the Mayor

By virtue of the authority vested in me as Mayor of the District of Columbia pursuant to section 422(2) of the District of Columbia Home Rule Act of 1973, as amended, approved December 24, 1973, Pub. L. No. 93-198, 87 Stat. 790, D.C. Official Code § 1-204.22 (2001 ed.), it is hereby ORDERED:

1. The Office of the Chief Medical Examiner (the "OCME"), in the exercise of its statutory authority under the Establishment of the Chief Medical Examiner Act of 2000, effective October 19, 2000 (D.C. Law 13-172; D.C. Official Code § 5-1401 *et seq.*) (2001), and subject to the legal restrictions and obligations imposed thereby, shall conduct autopsies upon the human remains of persons with mental retardation and developmental disabilities who receive services and support from the Mental Retardation and Developmental Disability Administration.
2. The OCME shall perform the autopsies required by paragraph 1 of this Order within 48 hours of receipt of the remains or as soon thereafter as practicable, assigning a priority to such autopsies consistent with the OCME's priorities established with respect to law-enforcement and public-health policies and procedures.
3. The OCME shall promptly forward the reports of autopsies conducted in accordance with paragraph 1 of this Order to the D.C. Mental Retardation and Developmental Disabilities Administration Fatality Review Committee established by Mayor's Order 2001-27 (Feb. 14, 2001).

4. EFFECTIVE DATE: This Order shall be effective nunc pro tunc to May 7, 2004.


ANTHONY A. WILLIAMS
MAYOR

ATTEST: 
SHERRYL HOBBS NEWMAN
SECRETARY OF THE DISTRICT OF COLUMBIA

Cause of Death by Calendar Year 2001

1. Acute Bronchopneumonia due to Alzheimer's Disease
2. Complications of Anal Squamous Cell Carcinoma
3. Hypertensive and Arteriosclerotic Cardiovascular Disease
4. Gram Negative Sepsis due to Acute and Chronic Pyelonephritis due to Immobilization due to Global Hypoxic-Ischemic Encephalopathy
5. *Pneumonia/Down Syndrome with Severe Mental Retardation
6. Hypertensive Atherosclerotic Cardiovascular Disease
7. *Pulmonary Embolus due to Post op perforated small bowel due to atonic bowel
8. Atherosclerotic and Hypertensive Cardiovascular Disease
9. Invasive Pancreatic Adenocarcinoma
10. Chronic Aspiration Pneumonia due to Cerebral Palsy and Mental Retardation due to Microcephaly of Unknown etiology
11. Hypertensive Cardiovascular Disease/Blunt Impact with Hip Fracture
12. Complications of Perforated Pre-pyloric Gastric Ulcer due to Helicobacter Pylori Gastritis
13. *Sepsis due to Aspiration Pneumonia due to Gastritis due to Chronic Bronchitis
14. Acute Pulmonary Thromboembolism due to deep venous thrombosis of the lower extremities due to impaired mobility due to cerebral infarct, atherosclerotic
15. Complications of Lobar Pneumonia due to Congestive Heart Failure due to Hypertensive Cardiovascular Disease/Decubitus Ulcer/Due to prolonged immobilization

16. *Complications of small Bowel Obstruction due to Fibrous Adhesions
Following remote Laparotomy for Appendectomy
17. Porencephaly and its sequelae
18. Acute peritonitis due to perforation of duodenum by migrated gastrostomy
feeding tube placed for treatment of porencephaly
19. Acute Bronchopneumonia due to Atherosclerotic Cardiovascular Disease
20. Hypertensive and Arteriosclerotic Cardiovascular Disease/Diabetes Mellitus
21. Complications of Aspiration Pneumonia due to Cerebral Aqueduct Stenosis
with hydrocephalus due to probable old leptomeningitis
22. *Fluvoxamine Intoxication
23. Pyelonephritis due to prolonged immobility following resection of ruptured
esophageal segment due to esophageo-gastric junction scarring after naso-
gastric intubation for treatment of small bowel obstruction after surgical repair
of perforated pyloric peptic ulcer
24. *Pneumonia/Chronic Obstructive Pulmonary Disease
25. Methicillin resistant staphylococcus aureus sepsis following cholecystectomy,
complicating Microcephaly due to infantile Meningoencephalitis
26. Complications of intestinal Obstruction of undetermined etiology
27. Choking with airway obstruction by sausage due to paranoid Schizophrenia
28. Seizure disorder due to global hypoxic-ischemic encephalomalacia, etiology
unknown.
29. Hypoxic Encephalopathy due to dislodgement of Tracheostomy tube placed
for treatment of pneumonia complicating Trisomy 21

** Causes of death for cases with an asterisk were determined by jurisdictions other than the District of Columbia*

**Cause of Death by Calendar Year
2002**

1. Metastatic Breast Carcinoma
2. *Cardio Respiratory Failure due to Down's Syndrome due to Seizures due to Dementia
3. Hypertensive and Atherosclerotic Cardiovascular Disease/Diabetes Mellitus/Sacral Decubitus
4. Streptococcus Pneumonia Septicemia, Complicating Sickle Cell Crisis due to Hemoglobinopathy HbS-Beta Thalassemia
5. Recurrent Bronchopneumonia due to Alzheimer's Dementia
6. Subacute viral Myocarditis
7. Acute Bronchopneumonia due to Cerebral Palsy
8. Blunt Impact Chest Trauma
9. Acute Bronchopneumonia due to severe Coronary Artery Atherosclerosis
10. Aspiration of Food Bolus
11. *Acquired Immunodeficiency Syndrome
12. * Cardio Pulmonary Arrest due to Sepsis Syndrome due to Enterococcal and Fungal Bacteremia
13. Hypertensive and Arteriosclerotic Cardiovascular Disease/Mental Retardation; Schizophrenia
14. Down Syndrome with Seizure Disorder and Pulmonary Complications
15. Metastatic Ovarian Carcinoma
16. Complications of Sickle Cell Disease
17. *Aspiration Pneumonia due to hypoxic encephalopathy

18. Recurrent Bronchopneumonia complicating Pulmonary Emphysema
19. Acquired Immunodeficiency Syndrome
20. Cerebral Palsy and Seizure Disorder of Undetermined Etiology
21. Bronchopneumonia due to Hypertensive Cardiovascular Disease
22. Cri Du Chat Syndrome
23. Gastrointestinal Hemorrhage due to Duodenal Ulcer
24. Hypertensive and Valvular Cardiovascular Disease

** Causes of death for cases with an asterisk were determined by jurisdictions other than the District of Columbia*

**Cause of Death by Calendar Year
2003**

1. Hypertensive Cardiovascular Disease
2. Gastric Necrosis and perforation associated with Hiatal hernia
3. Hypertensive Cardiovascular Disease
4. Bronchopneumonia due to Alzheimer's Dementia due to Down Syndrome
5. Recurrent Aspiration Pneumonia due to Cerebral Palsy with Mental Retardation, Spastic Quadriplegia and Scoliosis of unknown etiology/Hiatal hernia
6. *Pneumonia due to Dehydration due to Renal Insufficiency due to Myelodysplastic Syndrome
7. *Sepsis due to Sacral Decubitus Ulcers due to immobility due to Down's Syndrome
8. *Atherosclerotic Cardiovascular Disease
9. *Complication of Cerebral Palsy
10. Metastatic Adenocarcinoma, unknown primary
11. Seizure Disorder, undetermined etiology
12. Atherosclerotic Cardiovascular Disease with recent Coronary Artery Thrombus
13. Hemoptysis due to Erosive Tracheitis due to longstanding Tracheostomy for treatment of Pulmonary Emphysema/Hypertensive and Arteriosclerotic Cardiovascular Disease; Alzheimer's Disease
14. Recurrent Bronchopneumonia due to Mental Retardation of unknown etiology
15. Hypertensive and Arteriosclerotic Cardiovascular Disease
16. *Hypertensive Cardiovascular Disease
17. Complications of Cerebral Palsy
18. Hypertensive and Atherosclerotic Cardiovascular Disease

19. Hypertensive and Atherosclerotic Cardiovascular Disease
20. *Down's Syndrome
21. Acute Bronchopneumonia due to Immobility due to Congestive Heart Failure due to Hypertensive Cardiovascular Disease/Polymyalgia Rheumatica, Rheumatoid Arthritis
22. Seizure Disorder due to remote Blunt Impact Head Trauma
23. Hyperosmolar Coma Due to Diabetes Mellitus
24. Pulmonary Thromboembolism due to Deep Venous Thrombosis of the lower extremities due to reduced mobility due to hospitalization for Pneumonia due to Cerebral Palsy and Mental Retardation, etiologies unknown.
25. *Atherosclerotic Cardiovascular Disease
26. Metastatic Gastric Cancer
27. Septic Complication Following repair of Incarcerated Inguinal Hernia
28. Pulmonary Postirradiation Fibromatosis Following Radiation Therapy for the Treatment of Breast Cancer
29. Hypoxic-Ischemic Encephalopathy with Cortical Laminar Necrosis due to Presumed Birth Hypoxia-Ischemia, undetermined etiology
30. *Adult Respiratory Distress Syndrome due to Sepsis due to Aspiration Pneumonia/ Cri Du Chat Syndrome

** Causes of death for cases with an asterisk were determined by jurisdictions other than the District of Columbia*

**2001, 2002 & 2003 MRDDA
Fatality Review Committee Recommendations**

Appendix D

FRC Recommendation	Official Response
<ul style="list-style-type: none"> The FRC recommends the need for improvement in case management records, and the need for a special budget for MRDDA Wards residing more than twenty (20) miles outside of the District, for special institutional needs. 	<p>Records Management: MRDDA has hired a professional Records Manager to work under the supervision of a senior staff person. The Records Manager is drafting an updated policy.</p> <p>Special Budget: A budget request was included in the supplemental FY 2003 budget, the FY 2004 budget and has been carried over to subsequent annual budget requests.</p>
<ul style="list-style-type: none"> The FRC recommends that MRDDA institute a form for medication/dosages to be placed in the front of each District Wards record. Also, it recommended that a policy be developed to mandate that each District Ward receive annual health and dental assessments 	<p>Medication Dosage form: MRDDA has developed and distributed a "Medication Dosage Form". It is currently monitored by Quality Assurance Staff, and technical assistance is offered to Providers during monitoring visits.</p> <p>Annual health and dental assessments: DC Law 2.137 required that all MRDDA customers receive annual health and dental assessments prior to the development of their annual ISP. Additionally, MRDDA's Medical/Dental Policy requires these assessments annually.</p>
<ul style="list-style-type: none"> The FRC recommends that the Quality Council (in the Health Regulations Administration of DOH) perform an exploration of what mechanism either exists or can be readily developed such that MRDDA can enforce better long- term documentation on their customers. 	<p>The Quality Council will collaborate with MRDDA's Clinical Services Division in the ongoing project of documentation standards development for clinicians serving the MRDDA population.</p>
<ul style="list-style-type: none"> The FRC recommends for the Committee to develop protocols regarding closure of MRDDA FRC cases. 	<p>The Fatality Review Committee developed and is using a standard case closure protocol. This protocol will be incorporated in the FRC Handbook.</p>
<ul style="list-style-type: none"> The FRC recommends that a request be made to DHS General Counsel to provide any information regarding the District's policy on Do Not Resuscitate (DNR) order for MRDDA clients. 	<p>The Office of the Attorney General for the District of Columbia completed an in-depth review and determined that Do Not Resuscitate orders cannot be issued or authorized by the District or any of its agents.</p>
<ul style="list-style-type: none"> The FRC recommends that MRDDA develop a partnership with nursing facilities to ensure quality of care. 	<p>MRDDA has a comprehensive protocol that is activated for each consumer upon entering a nursing home. The consumer's residential placement is reviewed by the MRDDA Human Rights Advisory Committee to assure that consumers' rights are not violated prior to placement.</p>

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<ul style="list-style-type: none"> The FRC recommends that MRDDA oversee the placement of consumers in skilled nursing facilities with a medical professional review of coordination of care and the appropriateness of health care services delivered. 	<p>MRDDA has a comprehensive protocol that is activated for each consumer upon entering a nursing home. The protocol includes close medical, clinical and case management oversight and interaction with the nursing home staff.</p>
<ul style="list-style-type: none"> The FRC recommends that the KOBA Institute [or current contract agency] change the section of the investigative report from Recommendations to Suggestions, thereby reserving the term "recommendations: for the action the Committee formally proposes to address systemic issues or deficiencies. 	<p>Pending an Official Response: The KOBA Institute's emergency contract with the District to do investigations into the deaths of MRDDA customers has expired. The current contractor is the Columbus Organization. DHS and MRDDA will not adopt this recommendation due to their requirements of court supervision in the case. The court requires that "...investigations will result in written reports which include findings and recommendations".</p>
<ul style="list-style-type: none"> The FRC recommends that a viable policy on the refusal of treatment be developed, which takes into account the issue of competency and the provision of appropriate support, such as that client can make a good informed decision, and not avoid or he denied medical care for life threatening conditions. 	<p>Pending an Official Response: The "Surrogate Decision Making for Medical Care Act of 2002" has been drafted and submitted to the City Council for consideration and action. This legislation addresses issues of competency, standards and procedures to determine whether a customer can give "informed consent" to authorize or to refuse medical treatment. In those cases where the customer is unable to provide such consent, an independent panel will have the authority to determine whether substituted consent can be provided on behalf of the consumer. Once the legislation receives final approval by District officials and counsel, it will be submitted to the Council of the District of Columbia for legislative action.</p>
<ul style="list-style-type: none"> The FRC recommends that MRDDA conduct appropriate documentation and supervision [training] to meet the standards of the case management system. 	<p>MRDDA's Bureau of Case Management developed and implemented new performance standards for the Case Management System. These new performance standards are the measures by which case managers are rated in job performance. The standards measure case management tasks for completeness and accuracy. The Performance Standards provide supervisors with appropriate tool to measure and assess the case manager's performance of their specific duties, i.e., completing the required number of consumer visits, appropriate use of available tools, reporting requirements, etc.</p>
<ul style="list-style-type: none"> The Committee recommends that some guidelines be put in place at the residential facilities for the care of customer who for whatever reason are no able to participate in their day program. 	<p>Existing ICF/MR regulations, Medicaid Provider agreements and contracts contain standards that govern activities that should</p>

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<ul style="list-style-type: none"> The FRC recommends that Adult Protective Services provide education to MRDDA staff and service providers on APS reporting requirements. 	<p>Training about the APS law; adult abuse, neglect, and exploitation; reporting requirements; and how reports are investigated and risk reduction have been regularly provided as part of MRDDA's regular monthly training calendar. This calendar is published to the community as well as District staff.</p>
<ul style="list-style-type: none"> The FRC refers this case to the Quality Council and recommends a review of issues related to transportation of MRDDA clients, including incident reporting and the existence of and follow up to hospital discharge planning. 	<p>Pending an Official Response: MRDDA is addressing these issues. Progress is tracked by the Office of the Deputy Mayor for Children, Youth, Families and Elders via the Implementation Plan for an Interagency Coordination Memorandum Agreement.</p>
<ul style="list-style-type: none"> The Committee recommends that MRDDA explain the process and train the providers in the payment process for mental treatment for MRDDA customers, including Evans class members. 	<p>MRDDA Training Division and Contracts Bureau developed a protocol for payment and developed the training curriculum. The course is offered to Providers via MRDDA's monthly Training Calendar.</p>
<ul style="list-style-type: none"> The FRC recommends that providers ensure and document that the direct care staff are both competent in and currently certified in first aid and CPR. 	<p>Federal and local regulations require that Provider staff be certified in CPR and that current certifications are maintained in their personnel file. MRDDA's Training Division offers courses for first aid and CPR to community-based Providers and MRDDA staff on a regular basis, posed in the Monthly Training Calendar. MRDDA's Quality Assurance staff monitor for current CPR certification when surveying Providers.</p>
<ul style="list-style-type: none"> The Committee recommends that the Medical Assistance Administration increase its oversight of physicians to ensure necessary services are provided by physicians directly to MRDDA residents. 	<p>MAA is the single state agency delegated to the day-to-day administration of the District's Medicaid program and other health-care financing initiatives in the District. In cases where there is suspected Medicaid fraud, inappropriate billing or complaints concerning the delivery of Medicaid reimbursed services, MAA would investigate and take appropriate action. MAA does not have staff to perform oversight of physicians as a general matter and therefore does not support this recommendation.</p> <p>MAA, HRA, MRDDA, DOH, and the Board of Medicine hosted a "Physicians Forum" to discuss quality of medical supports and share consumer mortality reviews. This forum will be repeated, hosted by the Provider community and supported by MRDDA's medical staff.</p>

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	be made available to consumers who remain home from day programs due to illness or other reasons. Planned activities are also identified in the ISP to ensure that consumers are participating in their day programs or receiving active treatment when they are not in attendance.
<ul style="list-style-type: none"> The FRC recommends that the Office of the Corporation Counsel (OCC) conduct a comprehensive assessment of the issue of DNR orders for MRDDA clients. OCC may assemble a working group as needed to accomplish this task. 	The Office of the Attorney General for the District completed an in-depth review and determined that Do Not Resuscitate orders cannot be issued or authorized by the District or any of its agents.
<ul style="list-style-type: none"> The Committee recommended that nursing and group home should be staffed at adequate levels with properly trained personnel. The staff should monitor and document the care of MRDDA client and their adherence to internal quality assurance protocols on a routine basis. Group and nursing homes that do not have internal quality assurance measures should establish them. MRDDA should monitor compliance with these standards and report poor care and irregularities to the Health Regulation Administration. 	Federal and local regulations provide specific staff-to-consumer ratios for residential and day providers. These regulations also contain requirements for initial and periodic ongoing training for staff that provide support to consumers. Nursing and group homes are required by regulation to monitor care, keep clinical notes, document medication administration, and all other supports provided to consumers. These regulations hold the "Governing Body" of group and nursing homes responsible for upholding quality standards, and HRA, the enforcement arm for these groups, can and does enforce these regulations. MRDDA monitors group homes for performance and compliance with policy and standards, offers technical assistance when necessary, follows up on incidents and alert findings and refers to HRA for enforcement when other efforts are unsuccessful.
<ul style="list-style-type: none"> The FRC recommends that MRDDA develop policies regarding coordination of care in acute care facilities including a process for reporting issues related to quality of care. 	DHS currently has a protocol to address reporting issues related to quality of care, however, DHS has no jurisdiction or authority over acute care facilities. A protocol will be developed addressing MRDDA's response when customers are admitted to an acute care facility.
<ul style="list-style-type: none"> The FRC recommends that MRDDA develop procedures to address coordination of hospital discharge planning, pain management and follow up of end of life care. 	Pending an Official Response: MRDDA has developed a Comprehensive Health Care Plan that includes partnerships with the Departments of Health and Mental Health and community-based contracting partners as well. The Plan is the overall vehicle for providing coordinated medical support and care for MRDDA's consumers, and the Coordination of Care Policy is being developed to closely fit within the context of the Plan.

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	reviews and coordinate health care services for all consumers served.
<ul style="list-style-type: none"> The FRC recommends that DOH (MAA and HRA) and the OIG (MFCU) investigate the Washington Nursing Facility for concerns of neglect and failure to provide appropriate care, possibly causing or contributing to the deaths of patients. 	MAA responded: "The responsibility for investigation of deaths rests with the HRA. The MAA will coordinate with HRA regarding the quality of services rendered by providers who are reimbursed by DC Medicaid. If concerns are found related to the provision of care, or neglect then the fatality is cited and fined depending upon the deficiency. The case will also be referred to the OIG and MPD if needed".
<ul style="list-style-type: none"> The FRC recommends that ICF-MR's shall ensure that the appropriate clinical professionals (including but not limited to: nurses, speech pathologists, occupational therapists, nutritionists, and physical therapists) are required to monitor mealtime protocols, physical management (such as safe feeding and appropriate positioning), dysphagia issues, and aspiration, or high-risk individuals requiring specialized services. This monitoring plan must be incorporated in the ISP 	MRDDA supports this recommendation to the residential providers. MRDDA has protocols in place that must be followed when consumers change residences, whether the new residence is one operated by the consumer's current provider, or whether a different provider operates it. The Bureau of Case Management (BCM) manages coordination of consumer moves.
<ul style="list-style-type: none"> The FRC recommends that provider agencies follow the DC Code and health regulations process when conducting intra-provider discharging and transferring of consumers, and should include coordination with case managers, appropriate advance notice to the entity receiving the consumer, and a transition plan that includes health care coordination, specific individualized support that the consumer may need, and training that the receiving entity's staff may need to ensure a comprehensive transition for consumer and staff needs 	MRDDA supports this recommendation to the residential providers and recognizes that monitoring and enforcement mechanisms are in place via the Department of Health as the oversight authority. This recommendation has been published to the Providers through the IMIU Report, the bi-monthly newsletter developed by the DHS/Incident Management and Investigations Unit.
<ul style="list-style-type: none"> The FRC recommends that MRDDA develop a policy that requires providers to identify health risk factors, coordination of care issues, and implement strategies to address and mitigate the risks identified into the Individual Service Plan (ISP). 	Pending an Official Response: MRDDA's Comprehensive Health Care Plan addresses all of these issues. In addition, MRDDA has drafted a "Coordination of Care" policy that closely matches the coordinated support outcomes of the plan.
<ul style="list-style-type: none"> The FRC recommends that for MRDDA customers placed outside of the District, a formal reporting protocol should be established between the Department of Human Services, Incident Management and Investigations Unit and the regulatory entity in the jurisdictions of the placements. 	DHS will adopt this recommendation. As the Bureau of contracts updates, renews, re-issues new Human Care Agreements, a clause will be inserted requiring out-of-state providers to notify MRDDA of incidents that involve consumers under their care.
<ul style="list-style-type: none"> The FRC recommends that MRDDA develop a plan for building provider capacity for alternative community residential placements in the least restrictive environment for individuals with mental retardation. 	DHS will adopt this recommendation. The Public Consulting Group was retained by MRDDA to assist with a plan to implement the Home and Community Based Waiver. This plan will enable MRDDA to identify

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<ul style="list-style-type: none"> The FRC recommends that IMIU follow up on the deficiencies of the provider's performance as noted in Mortality Investigation. 	<p>The DHS/IMIU issued dispositions to Providers to ensure concerns are addressed. MRDDA has a process to conduct "Mortality Reviews" with residential providers who support MRDDA consumers that have expired. The Mortality Review Committee members include staff from the IMIU unit, MRDDA Clinical Services Division, Bureau of Case Management, and the Quality Assurance Unit. As soon as the mortality investigation is received for any deceased MRDDA consumer, IMIU staff contact the residential provider to schedule a Mortality Review Committee meeting. An established agenda is followed, and dispositions, corrective actions and recommendations are shared with Provider units of DHS and/or MRDDA as appropriate.</p>
<ul style="list-style-type: none"> The FRC recommends that death investigations shall include an interview of the primary care physician when healthcare and communication issues are identified 	<p>The DHS/IMIU Contract Manager for the investigation contract has communicated this recommendation to the contractor. The contractor will be monitored for compliance.</p>
<ul style="list-style-type: none"> The FRC recommends that MRDDA incorporate the integration of End of Life issues into consumers' person-centered plans as appropriate. MRDDA shall develop a training module on End of Life quality issues as part of the person-centered planning curriculum. 	<p>MRDDA's Training Division offers comprehensive End of life training to community stakeholders, including those who participate in consumer's IPS teams.</p>
<ul style="list-style-type: none"> The FRC recommends that the Nursing Board promulgate regulations that establish acceptable ratios of LPN's to ICF-MR facilities. 	<p>The Nursing Board is currently in the process of revising and updating regulations related to the scope of practice for registered and practical nurses and will take into consideration the recommendation to address staffing patterns for nursing personnel in residential settings.</p>
<ul style="list-style-type: none"> The FRC recommends providers ensure each consumer's quarterly medical review includes an assessment of prescribed medications. This must include a pharmacological review to determine whether the medications have any contra-indications with other medications, side effects, and/or food or dietary limitations that could impede the medication's effectiveness or, if taken in conjunction with the medication, could cause a consumer's diagnosis to worsen. The provider must ensure that the provider physician reviews, at least on a quarterly basis, the consumer's medication record for, but not limited to, medication errors, duplicate prescriptions, interactions and contra-indications. 	<p>This recommendation is under consideration by MRDDA. The major outcome for the Comprehensive Health Care Plan is to provide appropriate, timely medical supports to MRDDA consumers. As each consumer's health risk management plan is individually developed, monitoring intervals by clinical and medical staff are built in. Health interventions will be based on the findings of the scheduled monitoring by health professionals.</p>
<ul style="list-style-type: none"> The FRC recommends that MRDDA ensure that the oversight of clinical reviews and coordination of health care services on medically fragile individuals is conducted by the appropriate health care professionals. This will require that MRDDA assign adequate numbers of staff. 	<p>MRDDA is currently realigning its Clinical Services Division to meet the requirements of its Comprehensive Health Care Plan. The Plan required that MRDDA and community providers oversee clinical</p>

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	alternative, less restrictive residential settings and increase provider capacity. As Waiver Providers for residential services are approved (via MAA Provider Agreements and Human Care Agreements) consumers currently seeking less restrictive residential settings can choose to enroll in the waiver and receive these supports
<ul style="list-style-type: none">• The FRC recommends that MRDDA develop a general educational document highlighting healthcare coordination issues in serving MRDDA customers, to be distributed to the relevant healthcare community	Pending an Official Response: MRDDA has produced a Comprehensive Health Care Plan to provide coordinated medical supports to its consumers. This plan has been shared with the community Providers.

GOVERNMENT OF THE DISTRICT OF COLUMBIA

Department of Mental Health

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September 24, 2004

Dr. Marie Pierre-Louis
Acting Chief,
District Of Columbia Office of the Chief Medical Examiner

Dear Dr. Pierre-Louis:

Thank you for asking me to review the draft of the MRDDA Annual Report. As you know, I am sometimes called upon to evaluate MRDDA patients in my role as Director of the Neurology Service for the Department of Mental Health. We also see patients with similar neurological disorders in the DMH. Many of these patients have severe, and often incapacitating, neurological disorders which in turn predispose them to major medical complications and place them at increased risk of death from these complications. For example, patients with advanced Alzheimer's disease, major CNS infarctions, severe congenital brain disorders such as porencephaly or microcephaly, hypoxic encephalopathies, and other severe CNS disorders, are well known to be at heightened risk for developing aspiration pneumonia. Thus, it does not surprise me at all that the most prevalent cause of death between 2001-2003 in the MRDDA population was respiratory ailments. Many of the other illnesses that you mention in section III of your report are likewise medical conditions to which this population is especially susceptible. Moreover, because of impairment in their inability to communicate or obviously manifest their symptoms, which can be profound, these patients may not come to medical attention as quickly as one might hope -- despite being under the supervision of caregivers. This in turn further increases the likelihood of their demise before corrective medical action can be implemented or have a beneficial effect. In addition, the MRDDA patient population is at risk for the same kinds of common medical conditions that one sees in the general population, for example cardiovascular disease and cancer, which I note are also well represented as causes of death in Table 10.

I would suggest a minor change in Table 9 (Primary Neurologic Disorders), specifically to change the column heading "Cause of Death" to "Neurological Condition" since these conditions are not the actual or direct cause of death, but are predisposing conditions in most instances.

In summary, your findings for the 2001-2003 are not surprising to me, and would seem compatible with the heightened risk for certain medical complications that one expects to see in the MRDDA population.

Thank you for asking for my opinion, and please feel free to contact me if you have any further questions.

Sincerely,

Steven S. Wolf, M.D., Director, Neurology Service
St. Elizabeths Hospital, DC Department of Mental Health

