



District of Columbia
Mental Retardation and Developmental Disabilities

Fatality Review Committee
2005

Annual Report
Special Edition



Presented to

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EXECUTIVE SUMMARY

The Mental Retardation and Developmental Disabilities Fatality Review Committee presents the 2005 Annual Report/Special Edition. The Mental Retardation and Developmental Disability Fatality Review Committee was established in February 2001, by Mayor's Order 2001-27 and re-established in September of 2005 by Mayor's Order 2005-143. The Mayor's Order 2005-143 mandates that the Fatality Review Committee examine events that surround the deaths of individuals 18 years of age and older diagnosed with mental retardation and other developmental disabilities, which are wards of the District of Columbia or receiving care from the Mental Retardation and Developmental Disabilities Administration.

The Fatality Review Committee is comprised of members who represent public and private community organizations from a broad range of disciplines including health, mental health, education, 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 diagnosed with mental retardation and other developmental disabilities.

During calendar year 2005, 34 persons died who were diagnosed with mental retardation and other disabilities and served by the Mental Retardation and Developmental Disabilities Administration. The Fatality Review Committee reviewed 31 cases during the same calendar year. These reviews represented deaths that occurred during calendar years 2003 through 2005. During the fatality review meetings, the FRC examines an independent investigative report of each individual's death that includes a summary of the 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. Many of the fatality reviews lead to the identification of systemic health care and other service concerns. The Fatality Review Committee makes recommendations to promote comprehensive health care and improve the quality of life for persons diagnosed with mental retardation and other disabilities.

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

Summary of Findings for Deaths Reviewed in 2005

- 97% of the cases reviewed were autopsied
- 97% of the deaths were attributed to natural causes
- 43% of the decedents were over the age of 60 years
- 81% of the decedents died in a hospital setting
- 100% of the Fatality Review Committee's recommendations received responses

INTRODUCTION

This edition of the 2005 Annual Report is a summary of the work performed by the District of Columbia Mental Retardation and Developmental Disability Fatality Review Committee (hereinafter referred to as the FRC). It covers data that is specific to 31 decedents diagnosed with mental retardation and other developmental disabilities (MRDD) who received services from the Mental Retardation and Developmentally Disabilities Administration (MRDDA) and whose deaths were reviewed during the 12-month period between January 1, 2005 and December 31, 2005. It also provides an overview of decedents diagnosed with mental retardation and developmental disabilities whose deaths occurred over a six-year period from calendar years 2000 through 2005. This report focuses on mortality findings and related information pertaining to the overall care received by individuals with mental retardation and served by MRDDA.

The FRC was established in February 2001, under the auspices of the Office of the Chief Medical Examiner (OCME). It is a multi-disciplinary, multi-agency effort that was established for the purpose of conducting retrospective reviews of relevant service delivery systems and the events that surrounded the deaths of District wards or residents 18 years of age and older who received services from MRDDA. One goal of the FRC is to make recommendations to improve care and service delivery to these wards and residents.

Committee membership is broad, representing a range of disciplines and public and private agencies as well as community organizations and individuals. Membership includes representation from health, mental retardation, education, mental health, social services, public safety, legal and law enforcement areas. These professionals come together for the purpose of examining and evaluating relevant facets associated with services and interventions provided to deceased persons diagnosed with MRDD.

The fatality review process includes examination of relevant policies and statutes, independent investigative reports, and reports of forensic autopsies. This information highlights each deceased individual's social history, including family and care giver relationships, as well as living conditions prior to death; medical diagnosis and history; services provided; and cause and manner of death. These reviews examine compliance with District laws and regulations, agency policies and practices and recommendations by service providers. Many reviews result in the identification of systemic problems and gaps in services that may impact the consumers' quality of life. The FRC recommends systemic strategies to reduce the number of preventable deaths or improve the quality of life for persons diagnosed with MRDD who are under the care of MRDDA.

The District of Columbia Code defines mental retardation as a significantly "sub average general intellectual level" determined in accordance with standard measurements as recorded in the Manual of Terminology and Classification in Mental Retardation, 1973.¹ MRDDA's eligibility criteria for identification of persons with mental retardation are:

¹ D.C. Official Code §7-1301.03(19) (2001)

1. Current cognitive assessment (within 3 years prior to application date) with accepted IQ test scoring 75 or below. (If most recent testing or prior testing shows an IQ of 70 or above, an addition test within the past year may be required.)
2. Current adaptive assessment (within 3 years prior to application date) showing adaptive functioning in the Mild range or below, or indicating that the individual needs supports in at least 2 out of 10 areas of adaptive living.
3. A cognitive assessment before the age of 18 years showing IQ of 75 or below.

MRDD FATALITY REVIEW PROCESS

Since its establishment in 2001, the FRC has had the opportunity to evaluate some of the operational deficiencies and barriers associated with the fatality review process and the MRDDA system. These barriers have often impacted the FRC's ability to operate effectively, efficiently, and in the manner intended. The FRC members realize that many of the concerns that have surfaced are the result of an inability to anticipate the challenges associated with diversity of the distinct operating structures, laws, policies and practices of the various disciplines and agencies, which may conflict with the purpose and goal of the committee. Some of the more critical system obstacles include the following:

- **Document Ownership**

Since the creation of the FRC, there has been persistent confusion related to the distinction between the oversight operating structure provided by the Office of the Chief Medical Examiner (OCME) and related protocols for the FRC and the agency responsible for servicing the decedent population covered by the FRC, MRDDA. The FRC operates under the auspices of the OCME Examiner with oversight responsibility provided by the Deputy Mayor for Public Safety and Justice. The OCME has responsibility for the effective implementation of all fatality review processes that operate within the District, including MRDD, Domestic Violence, and Child Fatality Review Committees. The OCME Fatality Review Unit carries out these responsibilities.

The confusion has resulted in numerous problems for the FRC and has culminated in the need to clarify the roles and responsibilities of each group specifically related to the fatality review function, the lines of authority, confidentiality, public disclosure of information, the custody and maintenance of fatality review documents and related material, and other mandated reporting as required.

The FRC is responsible for conducting multidisciplinary, multi-agency reviews of only those deaths of individuals who were committed to and are under the care of MRDDA. This Administration, under the auspices of the Department of Human Services, and the Deputy Mayor for Children, Youth, Families and Elders, continues to serve as the primary public agency responsible for providing comprehensive

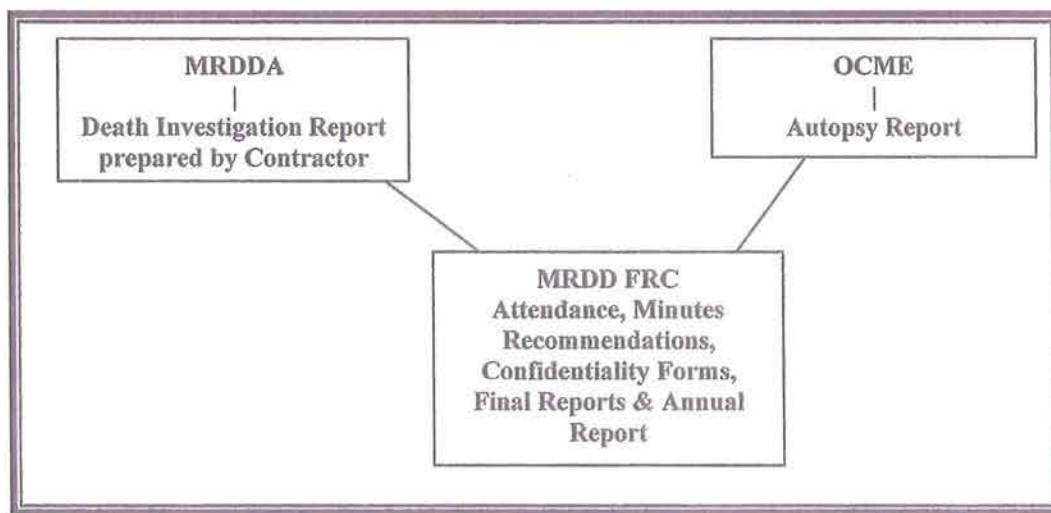
services and support to eligible District residents who are diagnosed with mental retardation or have developmental disabilities.

Critical documents for the FRC case review process include the death investigation report, prepared by a contractor under MRDDA, and the autopsy report, which is completed by OCME. Because the FRC does not generate these documents, they are not retained as a permanent part of the fatality review record. Those documents that are generated by the FRC include the following:

- Attendance Logs – documents attendance at fatality review meetings;
- Confidentiality Statements – signed by participants at each meeting;
- Meeting Minutes – summary of discussions related to general FRC business;
- Final Fatality Report – summary of the fatality review, that includes a brief description of the decedent, findings and recommendations;
- Recommendations – distributed to appropriate programs and agencies;
- Annual Report – published annually, reports data and recommendations that result from FRC case reviews.

Figure 1 below illustrates documents that are used during or developed from the fatality review process.

Figure 1:



- Death Investigative Reports

The primary document used during the FRC review is the individual death investigative report. As indicated above, an independent contractor, contracted through MRDDA, conducts the death investigation and prepares the reports. Since its creation in 2001, the FRC has experienced difficulty in obtaining the investigative reports in a timely manner. This problem has affected the FRC's ability to complete

reviews timely, determine appropriateness of the services provided, and make appropriate recommendations for services, policies, and legislative improvements. At the close of 2005, 48 deaths occurred between calendar years 2002 and 2005 that were out of compliance with the case review timeframes; due to investigative reports not completed for review by the FRC.

• FRC Recommendations

The fundamental goal of the fatality review process is to identify issues which impact citizens with mental retardation and intellectual disabilities, and practices that would reduce the number of preventable deaths and improve the overall quality of life. Thus, during case review meetings, risk factors, systems gaps/issues, and broad prevention strategies are highlighted. Historically, the majority of FRC recommendations have been geared towards improving services provided by MRDDA, its contractors, and other service providers. These recommendations are driven by the case-specific facts and information, including circumstances leading to and surrounding the individual's death. Once adopted by the FRC, they are forwarded to the appropriate public and private agencies and programs for consideration and response.

The FRC has struggled with the challenge of devising an effective strategy for assuring acceptance and implementation of recommendations. The FRC has established a mechanism for tracking and monitoring responses from relevant agencies and programs. Although responses to recommendations have increased, it has not resulted in ensuring that recommendations are implemented in a manner that affects broad systemic changes and improvements. As a result, the FRC continues to highlight problems that are directly related to appropriateness of care, compliance with policies, workforce development, end of life preparedness, guardianship concerns, and documentation.

The FRC has made recommendations to improve timeliness for obtaining information and data required for reviews, and improve the District's overall review process and collaborative methods of operating. Further, the FRC began to conduct a more thorough evaluation of the review process and operational modalities currently in place. It is the FRC's membership's hope that this evaluation will assist in identifying systemic issues and concerns that are obstructive to the process, and assist in devising ways to streamline information to allow the FRC to operate more efficiently.

MORTALITY FINDINGS

An important function of the FRC involves the analysis and review of MRDD consumer deaths to identify significant patterns and trends that may help increase knowledge about risk factors and provide information to help guide system enhancements. The FRC actively collects information pertaining to deaths of individuals diagnosed with MRDD and served by MRDDA. The following section provides a general description of the results of this analysis of deaths reviewed in calendar year 2005 (N=31) representing deaths that occurred during calendar years 2003 through 2005. As shown in Table 1 below, the total number of persons served by MRDDA for calendar years 2001 through 2005 ranged from 1547 to 1993. The actual number of deaths per year of MRDD decedents during this five-year span fluctuated between 26 and 36.²

Table 1: District of Columbia MRDDA Population and Deaths 2001 to 2005.

Year	Population	Number of Deaths	Percentage
2005	1993	34	1.7%
2004	1915	36	1.9%
2003	1790	31	1.7%
2002	1703	26	1.5%
2001	1547	32	2%

Table 2 below summarizes the number of cases by calendar year reviewed by the FRC since its inception. The total number of cases reviewed, (N=111) spans years 2001-2005.

Table 2: FRC Cases Pending Review

Year	Number of Deaths By Year N=159	Number Of Cases Reviewed By Year	Number of Cases Pending Review
2005	34	14	20
2004	36	25	11
2003	31	21	10
2002	26	19	7
2001	32	32	0
Total	159	111	48

Since 2001, the number of deaths reviewed by the FRC has increased yearly, from 9 in 2001 to 31 in 2005, a 41% increase. Table 2 also illustrates pending cases by calendar year.

² Information on the total population for each of the four years was provided by MRDDA, Consumer Information System (MCIS).

SUMMARY OF CASE REVIEW FINDINGS

The information contained in this section will cover the data and findings that resulted from cases reviewed during calendar year 2005 (N=31). Data in these tables also clearly specifies the year of the death despite the fact that the review occurred during 2005.

• AGE AND MORTALITY

In calendar year 2005, the FRC reviewed the deaths of 31 persons diagnosed with MRDD who ranged in age from 19 to 93 years. As with previous FRC years, the largest number of deaths identified and reviewed involved individuals who were over the age of 60 years. Of the 31 deaths reviewed, forty-three percent (N=13) were 61 years of age and older, Twenty-six percent (N = 8) were between the ages of 51 through 60 years; eighteen percent (N= 6) were ages 41 through 50; six percent (N=2) were 31 through 40, and three percent were between the ages of 21 through 30 (N=1) and three percent were 18 through 20 years (N=1). Table 3 below depicts the age ranges of the decedents by gender. As illustrated, there was no significant statistical difference in the number of male and female persons who died (N=15 and 16 respectively).

Figure 2: Age of Decedents Reviewed

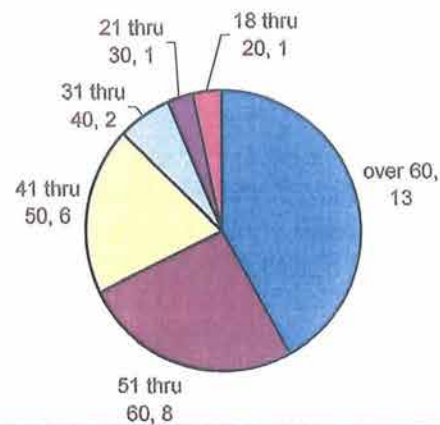


Table 3: Decedents by Age Range and Gender of Cases Reviewed (N=31)

Age Range	2003 N=5		2004 N=12		2005 N=14	
	Male N=3	Female N=2	Male N=4	Female N=8	Male N=8	Female N=6
18-20	1	0	0	0	0	0
21-30	1	0	0	0	0	0
31-40	0	0	1	1	0	0
41-50	0	0	1	1	3	1
51-60	1	0	1	2	2	2
61-over	0	2	1	4	3	3

Of the 2003 deaths reviewed (N=5), three were males who ranged in age from 19 to 57 years, and two were females who ranged in age from 65 to 84. Of the 2004 deaths reviewed (N=12), four were males who ranged in age from 37 to 68 years, and eight were females who ranged in age from 34 to 93 years. Of the 2005 decedents (N=14), eight were males who ranged in age from 41 to 75 years, and six were female who ranged in age from 48 to 87 years.

• RACE AND MORTALITY

Table 4: Decedents by Race for Cases Reviewed

Race N=31	2003		2004		2005	
	N=5	Average Age	N=12	Average Age	N=14	Average Age
Black	4	41	9	59	12	65
White	1	84	3	62	2	60
Other	0	N/A	0	N/A	0	N/A

Table 4 above illustrates the race of the 2005 decedents reviewed. Of the deaths reviewed (N=31), twenty-five, (80 %) were Black and, six (20%) were White. The average age of the Black decedents for all calendar years (N=25) was approximately 57 years. The average age of the White decedents for all calendar years (N=6) was approximately 65 years. Overall, the combined average age of death for the cases reviewed in 2005 (N=31) was 58 years. The following data describes the age and race of decedents for each year reviewed during calendar year 2005:

- The average age of death of the 2003 Black decedents (N=4) was 41 years and 84 years for the White decedent (N=1). The average age for the 2003 decedents combined (N=5) was approximately 50 years.
- The average age of death of the 2004 Black decedents (N=9) was 59 years and 62 years for the White decedents (N=3). The average age of death for the 2004 decedents combined (N=12) was approximately 60 years.
- The average age of death of the 2005 Black decedents (N=12) was 65 years and 60 years for the White decedents (N=2). The average age of death for the 2005 decedents combined (N=14) was approximately 60 years.

• WARD DATA

Ward of residence refers to the decedent's residential address at the time of the death. Addresses include natural homes, foster homes, Intermediate Care Facilities for persons with mental retardation (hereinafter referred as ICF/MR), supervised apartments, group homes and nursing homes. Figure 2 illustrates the Ward of Residence for the total number of cases (N= 31) reviewed in 2005. The largest number of cases reviewed involved individuals who resided in Ward Seven (N=13, or 43%), followed by Wards Five and Eight, with equal number of deaths (N=5). The decedents' ward or jurisdiction of residence at time of death by year of death is presented in Table 5.

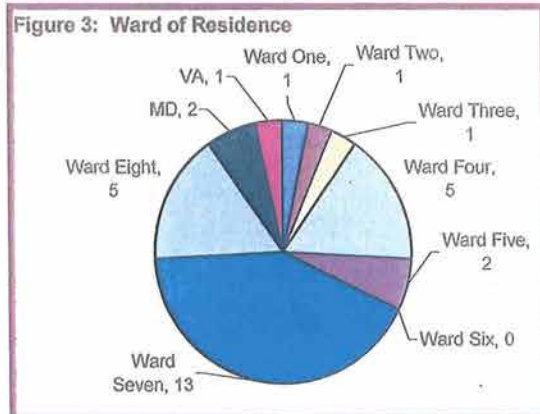


Table 5: Ward/Jurisdiction of Residence at Time of Death (N=31)

District Ward/ Jurisdiction	Deaths by Calendar Year		
	2003 N=5	2004 N=12	2005 N=14
One	1	0	0
Two	0	0	1
Three	1	0	0
Four	1	3	1
Five	0	2	0
Six	0	0	0
Seven	1	5	7
Eight	0	2	3
Maryland	1	0	1
Virginia	0	0	1

The largest number of deaths reviewed involved decedents who resided in the District of Columbia at the times of their deaths (N=28 or 90%). Three decedents had been placed by MRDDA in out-of-state facilities in Maryland and Virginia.

• **Decedents Residing in the District of Columbia**

- Of the 28 decedents who resided in the District at the time of their deaths, the largest number resided in Wards Four, Seven and Eight (N=23, or 82%) with the majority of these decedents residing in Ward Seven (N=13, or 46%).
- Of the five 2003 decedents, four (80%) lived in District, residing in Wards One, Three, Four and Seven. Three decedents (60%) lived in ICF/MR facilities and one decedent (20%) in a group home setting. The race of these four decedents included three Blacks and one White with their ages ranging from 19 to 84 with the majority over the age of 50 years (N=3).
- All of the 2004 decedents (N=12) lived in the District, residing in Wards Four, Five, Seven and Eight. Three decedents (25%) resided in Ward Four; two (16%) in Ward Five; five (42%) in Ward Seven, and two (16%) in Ward Eight. Of these decedents, eight (67%) lived in ICF/MR facilities, one (8%) in a group home facility, one (8%) in foster care, one (8%) in a nursing home and one (8%) at St. Elizabeth hospital. The race of the 12 decedents included nine Blacks and three Whites with their ages ranging from 37 to 93 years with the majority over the age of 50 (N=8).
- Of the 2005 decedents (N=14), 12 (86%) lived in the District, residing in Wards Two, Four, Seven and Eight. One decedent (7%) resided in Ward One; one (7%) in Ward Four; five (36%) in Ward 7 and two (14%) in Ward Eight. Six decedents (43%) lived in nursing home facilities and six (43%) in ICF/MR facilities. The races of these decedents included eleven Blacks and one White with their ages ranging from 41 to 87 with the majority over the age of 50 (N=8).

- **Decedents Residing in Out-of State Facilities**

- Of the 31 decedents reviewed in this report, 3 or 10% (one in 2003 and two in 2005) resided in out-of-state facilities. These decedents were in the care of MRDDA and had been placed in several types of facilities: one nursing home, one ICF/MR and one group home.
- Of the three out-of state decedents, two (66%) resided in Maryland and one (33%) resided in Virginia. The race of these decedents included two Blacks and one White with their ages ranging from 23 to 60 with 66% over the age of 50 (N=2).

- **Location at time of Death**

Of the cases reviewed, deaths occurred in locations that included hospitals, nursing homes, and group homes. Table 6 presents the number of decedents by year and location of death.

Table 6: Location at time of Death

Place of Death	2003 N=5	2004 N=12	2005 N=14
Hospital	5	8	12
Nursing Home	0	0	0
Hospice	0	0	1
Residential	0	4	1
Other, e.g., specialized home care (foster homes)	0	0	0

Of the 31 cases reviewed in 2005, 25 (81%) died in a hospital setting, five (16%) in residential settings and one (3%) in a hospice facility. This finding is relatively consistent with 2004 FRC Annual Report. Of the 25 decedents that died in a hospital setting, 14 (56%) were male and 11 (44%) were female. The average age of these decedents (N=25) was 59 years.

- **Cause and Manner of Death**

Pursuant to Mayor's Order 2004-76, "Autopsies of Deceased Clients of the Mental Retardation and Developmental Disability Administration",³ autopsies must be performed on all persons with MRDD who received services and support from MRDDA. Of the 31 cases reviewed, thirty decedents had autopsies (97%), and one decedent (3%) had no autopsy due to burial prior to OCME notification.

³ Mayor's Order 2004-76, Autopsies of Deceased Clients of the Mental Retardation and Developmental Disabilities Administration, May 13, 2004.

- Of the 2003 decedents (N=5), the District's OCME accepted jurisdiction and performed autopsies on three decedents (60%) and Maryland and Virginia each conducted one autopsy.
- Of the 2004 decedents (N=12), OCME accepted jurisdiction and performed autopsies on 11 decedents (92%) and one case was not autopsied.
- Of the 2005 decedents (N=14), OCME accepted jurisdiction and performed autopsies on 12 (86%) and one case was autopsied in Maryland and Virginia respectively.
- For all years combined (2003, 2004 and 2005), five autopsies (16%) were performed in out-of-state facilities, and in one case (3%) no autopsy was performed.

• **Cause of Death**

Consistent with observations in the general population of Washington, DC (see OCME Annual Reports 2003 and 2004), diseases of the cardiovascular system predominate as the most prevalent cause of death in the MRDD population reviewed. Ten cases were the result of Hypertensive and/or Atherosclerotic Cardiovascular disease; and one death was the result of Valvular Disease of the heart (Mitral Valve Insufficiency).

Table 7 lists the proximate causes of death or the underlying pathological condition responsible for the demise in the 31 cases reviewed. The cause of death⁴, as listed below, can bring death about by different mechanisms or terminal events such as arrhythmia, bronchopneumonia, asphyxia, etc.

Table 7: Cause of Death

Cause of Death	Number of Deaths N=31
Cardiovascular Diseases (Hypertension, Atherosclerosis, and Mitral Valve Insufficiency)	11
Infectious Diseases	6
Cancer (breast, ovary, and esophagus)	3
Primary Neurologic Disease	3
Gastrointestinal tract	2
Primary Pulmonary Conditions	2
Melodysplastic Disorder	1
Morbid Obesity	1
Therapeutic Complications	1
Choking (due to aspiration of a bolus of food)	1

The results in Table 7 indicate that infectious diseases followed Cardiovascular disorders in number with six deaths; 4 involving the respiratory system; one, the urinary tract; and

⁴ Cause of death is defined as the underlying pathological condition or injury that initiates the chain of events which brings about the demise.

one of the central nervous system. Infectious Diseases, specifically of the respiratory tract, for example, bronchopneumonia and pneumonia, were also the complicating terminal event in nine of the cases reviewed. Three deaths were due to cancer (breast, ovary, and esophagus); three causes were due to the primary neurologic disease. Two deaths resulted from disorders of the gastrointestinal tract, and two to primary pulmonary conditions. One death was the consequence of Myelodysplastic disorder, one was due to morbid obesity; complications directly related to treatment caused one death, and choking, due to aspiration of a bolus of food caused one death.

- **Manner of Death**

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 laboratory tests. Unlike the cause of death, manner can differ depending on the conditions and contributing factors revealed during the investigation and/or autopsy.

Table 8: Manner of Death by Year

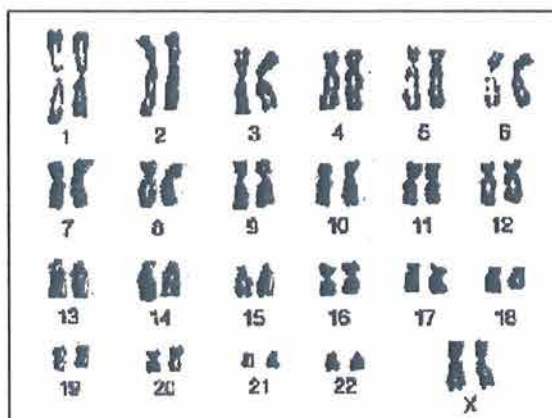
As shown in Table 8, the majority (N=30, or 97%) of the deaths reviewed were determined to be Natural; one (3%) was Accidental.

Manner of Death	Number N=31			Percentage
	2003 N=5	2004 N=12	2005 N=14	
Natural	5	11	14	97%
Accident	0	1	0	3%
Suicide	0	0	0	0
Homicide	0	0	0	0
Undetermined	0	0	0	0

Down Syndrome: An Educational Overview

Each year, the FRC would like to take the opportunity to share an educational overview of various disorders that affect the MRDD population in the District. This year, we present an educational overview of Down syndrome. Down syndrome is defined as the most common and readily identifiable chromosomal condition associated with mental retardation and is caused by a chromosomal abnormality. For some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth. Down syndrome is a genetic condition caused by extra genetic material (genes) from the 21st chromosome. Research has linked an association between a mother's age and the chances of having a baby with Down syndrome.

This is a picture of a normal set of chromosomes. Note the 22 evenly paired chromosomes plus the sex chromosomes. The XX means that this person is a female. The test in which blood or skin samples are checked for the number and type of chromosomes is called a karyotype, and the results look like this picture. The incidence of Down syndrome has been reported as 1 in 800 live births to 1 in 1,100 live births. A recent estimate in the United States puts the incidence at about 1 in 1,000. There is much speculation on the cause of Down syndrome due to chromosomal abnormalities. Nationally, the average of age of death of individuals with Down syndrome is 55.8 years. The Down Syndrome life expectancy has also been found to be dependent on the intelligence of the person with Down Syndrome. The Down Syndrome life expectancy of a 1-year-old child with Down syndrome with IQ 45 to 70-mild/moderate intellectual retardation is around 55 years. With IQ 19 or below - profound mental retardation - the Down syndrome life expectancy is about 43 years. (Based on research carried out by Strauss D, Eyman RK, 1996).



In the District of Columbia, the mean age of death for the six individuals diagnosed with Down Syndrome is 54 years, 8 months, about one year less than the national average. This average, 54-8, may be spuriously high. The range of age at death is from 45 years to 73 years, 3 months (R = 28-3) and the median is 52-2 (45, 47-8, 50-2, 54-4, 58-10 and 73-3). Obviously (for our sample of six decedents ages at death) there is a significantly high outlier. However, without knowing the number of cases, range, and median, of the national sample or population that the mean of 55.8 is based upon, we cannot know if our mean of 54.8 is significant (statistically).

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- Poor muscle tone
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds)
- Hyper flexibility (excessive ability to extend the joints)
- Short, broad hands with a single crease across the palm on one or both hands
- Broad feet with short toes
- Flat bridge of the nose
- Short, low-set ears
- Short neck
- Small head
- Small oral cavity

Individuals with Down syndrome are usually short in stature, and the physical as well as intellectual development is slower. Besides having a distinct physical appearance, individuals with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes them more prone to respiratory problems. Visual problems such as crossed eyes and far-or nearsightedness are higher in those with Down syndrome, as are mild to moderate hearing loss and speech difficulty. Approximately one third of babies born with Down syndrome have heart defects, and some are born with gastrointestinal tract problems that can be corrected. Others with Down syndrome also may have a condition where a misalignment of the top two vertebrae of the neck occurs. This condition makes these individuals more prone to injury if they participate in activities that overextend or flex the neck. Persons with Down syndrome may have a tendency to become obese, as they grow older. Besides having negative social implications, the extra weight threatens these individuals' health and longevity.

• Neuropsychiatric Disorders

Table 9 provides a numerical summary of the first two axis' of the Mutiaxial System (DSM-IV-TR). Axis I is for reporting Clinical Disorders or conditions and Other Conditions That May Be a Focus of Clinical Attention. In addition, Axis I is for reporting Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence excluding Mental Retardation. Axis II is for reporting Mental Retardation and Personality Disorders. Mental Retardation has been distinguished by cognitive functioning, adaptive functioning and level of severity. When significant neurologic dysfunction is associated with other organ system anomalies, an individual's life expectancy may be shortened.

Table 9: Neuropsychiatric Disorders by Axis

Axis I		Axis II		
Disorders	Decedents N=10	Level of Severity	Decedents N=31	
			Cognitive	Adaptive
Intermittent Explosive Disorder	2	Mental Retardation Profound	12	14
Depressive Disorder NOS	1	Mental Retardation Severe	8	10
Dementia NOS	2	Mental Retardation Moderate	8	5
Psychotic Disorder	1	Mental Retardation Mild	3	2
Schizophrenia	3			
Organic Mood Disorder	1			

These are the various underlying Neuropsychiatric Disorders reported singularly or in combination in the 2005 (N=31) cases reviewed. The degrees of severity reflect the level of intellectual (cognitive) impairment. Of the deaths reviewed (N=31), twelve, (38%) were diagnosed with Profound Mental Retardation, eight (26%) were Severe, eight (26%) were Moderate, and three (10%) were Mild.

2005 RECOMMENDATIONS

During calendar year 2005, the FRC reviewed 31 cases and made 13 new recommendations and re-issued 10 recommendations from previous years. These recommendations were made in the areas of health, safety, guardians and end-of-life preparedness. Concerns regarding guardianship and end-of-life issues continue to be prominent. As such, over the past five years the FRC has made 19 recommendations. Additionally, the FRC created a subcommittee to review all previous recommendations in these categories. This subcommittee presented an overview to the Deputy Mayor for Children, Youth, Families and Elders regarding the persistence of these problems. There were also a number of other systemic concerns related to continuity of care, documentation, staff competency, and training. The 13 FRC recommendations issued in 2005 are as follows:

1. MRDDA should ensure that at a minimum, persons with complex medical issues, terminal illnesses and/or other significant medical compromise have a legal guardian appointed to act in their best interest and assist in making major life/end of life decision when the consumer is without family or guardians. This process should be reinforced in the Individual Service Plans.
2. DHS/IMIUI shall educate/inform the Columbus Investigative Group of Quality Trust's role in relationship to the appointment of advocates.
3. DHS/IMIUI should educate the Columbus Investigative Group on District of Columbia laws and policies regarding DNR and End of Life issues.
4. MRDDA should review the 199 high-risk customers to ensure the appointment of medical guardians and specify the medical issue(s).
5. MRDDA should invite the staff of the Office of the Attorney General (OAG) to provide mandatory training on capacity and guardianship for at-risk consumers.
6. MRDDA should send a reminder to the provider community regarding MRDDA's Medical Care Protocols.
7. MRDDA should develop policies/standards that define their expectations of providers as related to health care.
8. DHS/IMIUI shall requests that the Columbus Investigative Group record the diagnoses according to the DSM IV [TR].
9. DHS/IMIUI shall review the Child Fatality Review Committee's (CFRC) protocols for developing a consumer-centered mortality review.
10. DHS should prepare and present a plan to manage the seven (7) outstanding 2002 investigations of non-class members.
11. MRDDA should ensure that providers train and conduct competency-based reviews of staff, consultants, volunteers, etc., regarding health care coordination of consumers.
12. MRDDA should initiate and lead discussions with authorities, agencies and stakeholders regarding contractual arrangements with primary care physicians.
13. MRDDA case managers should be trained on the ISP process to ensure documentation is being followed through successfully.

OVERVIEW FOR CALENDAR YEARS 2000 THROUGH 2005

During calendar year 2005, the FRC conducted a retrospective review of death trends from calendar years 1991 through 2005.⁵ As in most retrospective reviews, a major barrier was locating data because some information was difficult to obtain or no longer existed. For example, many death certificates lacked information on type of residence where the decedent lived at the time of death, or information on health care interventions provided. Thus, as Table 10 illustrates, the FRC was able to gather partial information related to fatalities for calendar years 1991 through 1999. Due to these data gaps, the FRC was limited in its ability to fully analyze this information. Therefore, data from 1991 through 1999 calendar years is provided as a historical reference only and the major emphasis of this analysis focuses on more complete data for calendar years 2000 through 2005.⁶

Table 10: District of Columbia MRDDA Population and Deaths 1991 to 2005

Year	Population	Number of Deaths N=372	Percentage
2005	1993	34	1.7%
2004	1915	36	1.9%
2003	1790	31	1.7%
2002	1703	26	1.5%
2001	1547	32	2%
2000	1608	25	1.5%
1999	Unavailable	24	Unavailable
1998	1354	23	1.6%
1997	Unavailable	16	Unavailable
1996	Unavailable	17	Unavailable
1995	814	17	2%
1994	Unavailable	27	Unavailable
1993	Unavailable	15	Unavailable
1992	Unavailable	13	Unavailable
1991	Unavailable	36	Unavailable

- Results presented in Table 10 indicate the number of MRDD deaths between 2000 and 2005 (range 25 to 36), as well as data that could be gathered for years 1995-1999.
- It appears that deaths have historically represented 1.5% to 2% of the total MRDDA client population annually for years 2000 through 2005 (N=184).
- IMIU policies were first instituted in 1999. These policies mandated the reporting of all MRDDA consumer deaths and are still in existence.

⁵ MCIS.

⁶ MRDDA Death Listing from 1991- Sorted by Date

• **GENDER AND MORTALITY**

Table 11 presents information on the gender of the persons who died during 2000-2005 and received services from MRDDA. During these review years, men died (N=102, or 56%) at a slightly higher rate than women (N=82, or 44%). There were approximately equal numbers of males and females who died during 2000, 2001 and 2003. In 2002, 2004 and 2005, there were slightly larger percentages of males than females among the deceased.

Table 11: Deaths by Gender for calendar years 2000-2005-year period (N=184)

Year	Gender				Total N=184
	Males		Females		
	Number of Deaths	Percentage	Number of Deaths	Percentage	
2000	13	52%	12	48%	25
2001	15	47%	17	53%	32
2002	18	69%	8	31%	26
2003	16	52%	15	48%	31
2004	19	53%	17	47%	36
2005	21	62%	13	38%	34

As illustrated in Table 11, overall more males than females died over the six-year period. The following are findings related to gender of the 184 decedents by calendar year:

- Of the 2000 decedents (N=25), thirteen were males who ranged in age from 28 to 85 years, and twelve were females who ranged in age from 30 to 100.
- Of the 2001 cases reviewed (N=32), fifteen were males who ranged in age from 22 to 80 years, and seventeen were females who ranged in age from 24 to 82 years.
- Of the 2002 decedents (N=26), eighteen were males who ranged in age from 28 to 87 years of age, and eight were females who ranged in age from 45 to 79 years.
- Of the 2003 cases reviewed (N=31), four were males who ranged in age from 19 to 86 years, and eight were females who ranged in age from 19 to 85 years.
- Of the 2004 decedents (N=36), nineteen decedents were males who ranged in age from 19 to 79 years, and seventeen decedents were females who ranged in age from 22 to 93 years.
- Of the 2005 decedents (N=34), twenty-one were males who ranged in age from 38 to 86 years, and thirteen were females who ranged in age from 23 to 87 years.

Figure 4 below illustrates the average age of death for the total population during the six-year review period. The average age of death appeared to be consistent, about 57 years. A review of each year indicates that in 2000 the average age of death was fifty-seven years, fifty-three years for 2001, sixty years in 2003 and fifty-eight years of age in 2002, 2004 and 2005.

Figure 4

• **AGE AND MORTALITY**

Table 12 and Figure 4 below illustrate the number of deaths by age range for each year reviewed. The correlation between age and mortality shows the expected trend, with mortality increasing as the population served by MRDDA ages.

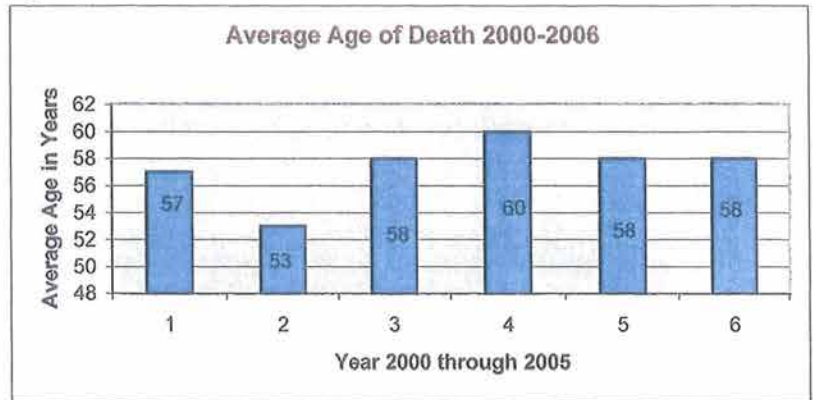


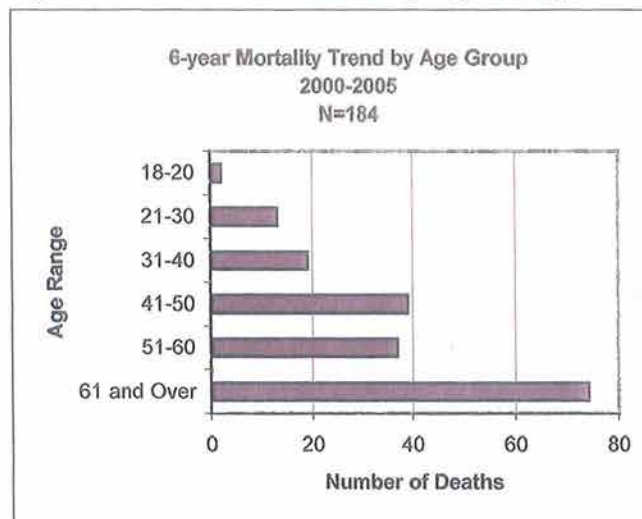
Table 12: Age and Mortality by Calendar Years 2000-2005

Age	2000 N=25	2001 N=32	2002 N=26	2003 N=31	2004 N=36	2005 N=34	Total N=184
18-20	0	0	0	2	0	0	2
21-30	2	4	1	4	1	1	13
31-40	5	6	3	0	4	1	19
41-50	4	5	7	6	7	10	39
51-60	2	5	3	7	10	10	37
60+	12	12	12	12	14	12	74

The largest number of deaths were of persons 61 years of age and older for each calendar year reviewed. Of the 184 deaths from 2000-2005, 74 or, 40% were 61 years of age or older; 37 or, 20% were ages 51-60; 39, or 21% were ages 41-50; 19, or 10% were ages 31-40; 13, or 7% were between 21-and 20; and 2, or less than 1% of the deaths were of individuals 18-20 years.

Overall, the relationship between mortality and age continued to show the expected trend of mortality increasing with age for the combined calendar years. After the age of 50 years, the death rate increases dramatically, in line with overall population trends.

Figure 5: Number of Deaths by Age Range



• RACE

As shown in Table 13 table below, over the 6-year span, 2000-2005, more Blacks (N=131, or 71%) died than White or others (N=53, or 29%). This pattern is consistent with the racial composition of MRDDA's overall customer population.

Table 13: Race of MRDDA Decedents 2000-2005

Year Number of Deaths N=184	Total Black N=131	Total White N=43	Total Hispanic N=1	Total Native American	Total Asian	Total Other/ Unknown N=9
2000 N=25	13	3	N/A	N/A	N/A	9
2001 N=32	24	8	N/A	N/A	N/A	0
2002 N=26	17	9	N/A	N/A	N/A	0
2003 N=31	23	8	N/A	N/A	N/A	0
2004 N=36	28	7	1	N/A	N/A	0
2005 N=34	26	8	0	0	0	0

*N/A: Data unknown and unavailable at this time (see below).

The average age of the Black decedents (N=131) was approximately 53 years of age, and 66 years for the White/other decedents (N=53). According to the National Vital Statistics Reports; vol. 50 no 15, the average life expectancy for District residents by race (1989-1991) was 64.4 years for African Americans, and 76.1 years for Whites.⁷

⁷ Information provided for calendar years 2000 and 2001 did not provide conclusive information on race. In 2002, MRDDA initiated a Consumer Information System (MCIS) in which information was a required field. The number of consumers with race marked as "other" was determined by MCIS.

Life Expectancy in the District of Columbia An Overview

According to the National Vital Statistic Report, 2002, life expectancy is a comparative measure of longevity often used to gauge the overall health of a population. Life expectancy is the average number of years remaining to be lived by those surviving to that age on the basis of a given set of age-specific death rates. However, life expectancy at birth represents the average number of years that a group of infants would live if the infants were to experience throughout life the age-specific mortality rates in a given period (Anderson et al., NCHS, 2002). Life expectancy at birth is strongly influenced by infant and child mortality. On the average, life expectancy at birth for the United States was 76.9 years in 2000, an increase of 0.2 years from 1999 (Minin et al., NCHS, 2002). Despite no increase in life expectancy between 1998 and 1999, the general trend observed in U.S. life expectancy has been upward throughout the 20th century (Anderson et al., NCHS, 1999).

There are marked differences in life expectancy at birth by race and gender for the total population of the U.S., with females tending to live longer than males and whites living longer than black/African Americans. For the U.S. in 2000, life expectancy for females was 79.5 years, while life expectancy for males was 74.1 years. Therefore females, on the average, lived 5.4 years longer than males. In 2000, life expectancy for whites was 77.4 years compared with the life expectancy for black/African Americans that was 71.7 years, a difference of 5.7 years between the white and black/African American populations.

Among the four major race-gender groups (Table 4), white females continued to have the highest life expectancy at birth (80.0 years), followed by black/African American females (74.9 years), white males (74.8 years), and black/African American males (68.2 years). Between 1999 and 2000, life expectancy increased 0.4 year for black/African American males from 67.8 years in 1999 to 68.2 in 2000. Black/African American males experience annual increases in 1990-1992 and 1994-2000 (NCHS, 2002). Life expectancy for black/African American females climbed from 74.7 years in 1999 to 74.9 years in 2000, an increase of 0.2 year. From 1999 to 2000, life expectancy for white males increased 0.2 year from 74.6 years to 74.8 years. White female life expectancy increased during the same period by 0.1 year from 79.9 years to 80.0 years. Overall, the largest gain in life expectancy between 1980 and 2000 was for black/African American males (4.4 years).

The most current life tables published by the United States National Center for Health Statistics (NCHS) for the District of Columbia are for the average lifetime in years, 1989-1991. Therefore, from 1989-1991, the average three-year life expectancy at birth for the residents of the District of Columbia was 68.0 years, which was ranked 51 among the states. Nonetheless, the District of Columbia followed the general pattern of the United States females tend to live longer than males and whites live longer than black/African Americans. For the District, the average life expectancy for females was 74.2 years or 12.2 years longer than males whose life expectancy averaged 62.0 years from 1989-1991. There are also similar differences in life expectancy at birth by race. Whites (76.1 years), on the average, lived 11.7 years longer than black/African Americans (64.4 years).

Comparing the four race-gender groups, white females who lived in the District had the highest life expectancy at birth (81.6 years); followed by black/African American females (71.6 years), white males (71.4 years), and black/African American males (57.5 years). The longevity of each of these four groups mirrored the exact pattern of the nation. Although NCHS has not computed comparable life expectancy data for 1999 by states, it is interesting to note that from 1989-1991, White female D.C. residents (81.1 years) tied ranking third with other white females among the other states. For states with black/African American population, both D.C. resident black/African American males and females ranked last, that is, they tend to die younger than the general U.S. population.⁸

Average Life Expectancy at Birth by State for 2000

State	Life expectancy at birth Total	Life expectancy at birth Male	Life expectancy at birth Female
District of Columbia	72.6	68.5	76.1
Maryland	76.3	73.6	78.8
Virginia	76.9	74.3	79.1

Population Division, Interim State Population Projections, 2005, and us Census Bureau Internet Release Date: April 21, 2005
(See Appendix E for Full Chart)

Increased Longevity of Persons with Developmental Disabilities

Persons diagnosed with MRDD are also experiencing increases in their lifespan. The mean age at death for persons with mental retardation was 66 years in 1993 up from 19 years in the 1930s and 59 years in the 1970s. Further, with continued improvement in their health status, individuals with mental retardation—particularly those without severe impairments—could be expected to have a lifespan equal to that of the general population. Longevity has also increased dramatically for persons with Down syndrome. Average age at death for persons with Down Syndrome in the 1920s was 9 years; it rose to 31 years in the 1960s and to 56 years in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999).⁹

⁸ Monograph, District of Columbia State Profile, Department of Health, State Center for Health Statistics Administration, December 2003

⁹ The State of the States in Developmental Disabilities: 2002 Study Summary

• MORTALITY AND RESIDENCE

The mortality and residential information in this section is provided to offer an overview of the type of residential settings of 184 decedents lived in at time of death.

Table 14: Residential Facilities

Facility Type N=184	2000 N=25	2001 N=32	2002 N=26	2003 N=31	2004 N=36	2005 N=34
Intermediate Care (ICF)	15	10	10	17	20	13
Nursing Home	1	10	5	6	9	11
Natural Home	4	5	2	2	2	5
Community Residential (CRF)	1	2	4	0	1	5
Other (Specialized home care,	4	5	5	6	4	0

As indicated in Table 14, of the 184 decedents, more resided in Intermediate Care Facilities (ICF/MR) than other residential facilities (85, or 46%) from 2000 through 2005. Forty-two decedents (23%) resided in nursing home facilities, 20, or 11% lived in their natural homes, thirteen, or 7% lived in Community Residential Facilities (CRF), and twenty-four, or 13% lived in Specialized Home Care (foster homes), supervised apartments or other settings.

- Of the 2000 decedents (N=25), 15 decedents lived in ICF/MR facilities. Twelve decedents resided in Ward Seven; one in Wards One and Four respectively, and one in Maryland. One decedent lived in a nursing home facility located in Ward Eight; four decedents lived in their natural homes three of which were located in Ward Four and one Ward Six. One decedent lived in a community residential facility in Ward Four; and two decedents lived in supervised apartments, one in Ward One and Four respectively. Two decedents lived in unidentified facilities both of which were located in Ward Four.
- Of the 2001 decedents (N=32), 10 lived in ICF/MR facilities. Five resided in Ward Four, two in Ward Seven, and one in Wards One and Eight respectively. Ten decedents also resided in nursing homes located, three of which were located in Ward Seven, three in Maryland, two in Ward Six, and one in Wards One and Eight respectively. Five decedents lived in their natural homes two of which were located in Ward Eight, one in Wards One and Four respectively, and one in Maryland. Two decedents lived in supervised apartments both of which were located in Maryland, one lived in specialized home care (Foster care) located in Ward Seven, and two lived in hospitals located in Wards One and Eight.
- Of the 2002 decedents (N=26), 10 lived in ICF/MR facilities. Four resided in Ward Seven, two in Ward Four, one in Wards One, Two, and Five respectively, and one was lived in Maryland. Five decedents resided in nursing homes, two in Ward Six, one in Ward Seven and two in Maryland. Two decedents lived in their natural homes located in Ward Four. Four decedents resided in Community Residential Facilities (CRF), one in Wards Four, Six and Seven respectively, and one in Maryland. Finally, two decedents lived in supervised apartments both of

which were located in Maryland. Two decedents lived in hospital settings located in Ward Six and Maryland, and one decedent lived in an unidentified facility located in the state of Pennsylvania.

- Of the 2003 decedents (N=31), 17 lived in ICF/MR facilities. Seven resided in Ward Seven; three were located in Wards One, Four and Five respectively, and one was located in Ward Eight. Six decedents resided in nursing homes, one located in Wards Three, Six, Seven and Eight respectively, and two were located in Maryland. Two decedents resided in their natural home; one was located in Ward Two, and one in Maryland. Lastly, three decedents lived in specialized home care all of which were located in Maryland. One decedent resided in a supervised apartment located in Maryland, one resided at a treatment facility in Florida, and one resided in a facility in Texas.
- Of the 2004 decedents (N=36), 20 were placed in ICF/MR facilities. Of these, ten lived in Ward Seven, three in Wards Five and Eight respectively, two in Ward Four, and one in Wards One and Six respectively. Nine decedents lived in nursing home facilities, two of which were located in Ward Seven, one in Wards Two and Five respectively, two in Virginia, and three in Maryland. Two decedents resided in their natural homes in Wards Seven and Eight. One decedent resided in a CRF located in Ward Seven; one decedent resided in Specialized Home Care in Ward Four; one resided in St. Elizabeths Hospital in Ward Eight, and two resided in supervised apartments in Wards Four and Seven.
- Of the 2005 decedents (N=34), 13 were lived in ICF/MR facilities. Six decedents lived in Ward Seven, two in Wards Four and Eight respectively, and one in Wards Two, Five and Six respectively. Eleven decedents resided in nursing home facilities of which six were located in Ward Seven, one in Wards Five, Six and Eight respectively, one in Maryland and Virginia. Five decedents resided in their natural homes, two were located in Wards Six and Seven respectively, and one in Ward Four. Lastly, five decedents resided in CRF's, one in Wards One, Four and Six respectively, and two in Maryland.

During calendar years 2000-2005, the majority of the decedents resided in the District at the time of their deaths (n = 151, or 83%). Thirty-three decedents (17%) were residents of other states, twenty-seven resided in Maryland, three in Virginia, one each in Pennsylvania, Florida, and Texas. These decedents were placed in out-of-state facilities by MRDDA. The distribution of these decedents diagnosed with MRDD who sought services by MRDDA must be viewed as a function of the distribution of service providers in the District of Columbia. Some decedents resided in Wards because of their residential placements, not necessarily because they were born there.

As indicated below in Table 15, the majority of decedents over the six-year review period who lived in the District resided in Ward Seven (N=62). Of the decedents residing in out-of-state facilities, (N=33, or 18%) the majority resided in the state of Maryland (N=27).

Table 15: An Overview of Ward Data by Calendar Year (2000-2005) N=184

Year	Ward 1 N=14	Ward 2 N=4	Ward 3 N=1	Ward 4 N=30	Ward 5 N=10	Ward 6 N=14	Ward 7 N=62	Ward 8 N=16	Other States N=33	
2000 N=25	2	0	0	8	0	1	12	1	MD	1
									VA	0
									Other	0
2001 N=32	6	0	0	6	0	2	7	5	MD	6
									VA	0
									Other	0
2002 N=26	1	1	0	5	1	4	6	0	MD	7
									VA	0
									Other	1
2003 N=31	3	1	1	3	3	1	8	2	MD	7
									VA	0
									Other	2
2004 N=36	1	1	0	4	4	1	15	5	MD	3
									VA	2
									Other	0
2005 N=34	1	1	0	4	2	5	14	3	MD	3
									VA	1
									Other	0

LEVEL OF DISABILITY AND MORTALITY (CALENDAR YEARS 2004-2005)

Mental Retardation is not necessarily associated with an increased premature death rate. However, certain key disabilities can be used to accurately predict life expectancy in individuals with cerebral palsy and mental retardation. These include: (1) presence and severity of mental retardation, (2) inability to speak intelligible words, (3) inability to recognize voices, (4) inability to interact with peers, (5) severity of physical disability, (6) use of tube feeding, (7) incontinence, and (8) presence and severity of seizures.¹⁰

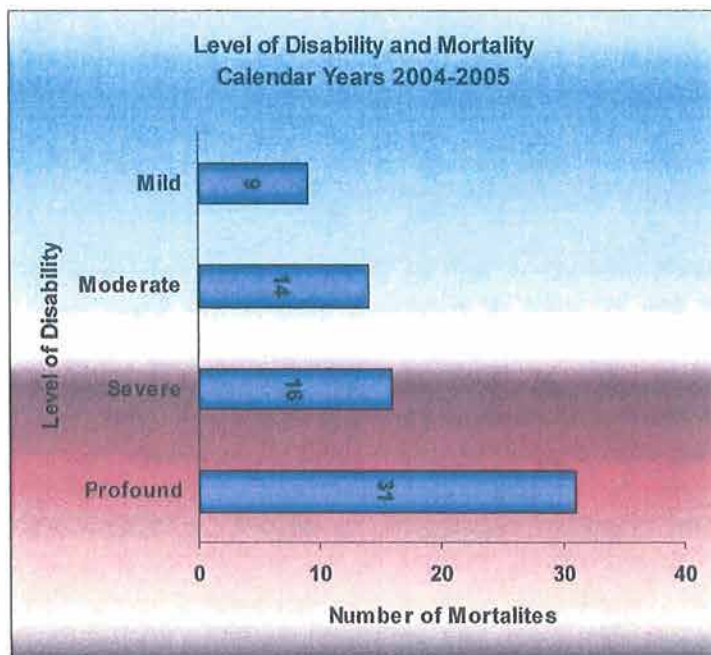
Individuals with severe to profound cognitive impairment, in addition to age, race and gender, experience a decreased life expectancy related to the underlying etiology or additional complicating disorders. Neurologic dysfunction resulting in immobility, significant oral motor dis-coordination, dysphasia, and aspiration confers a greater risk of premature death than mental retardation itself. When significant neurologic dysfunction is associated with other organ system anomalies, an individual's life expectancy is shortened further. The degrees of severity reflect the level of intellectual (cognitive) impairment:

- Mild Mental Retardation - IQ level 50-55 to approximately 70
- Moderate Retardation - IQ level 35-40 to 50-55
- Severe Mental Retardation - IQ level 20-25 to 35-40
- Profound Mental Retardation - IQ level below 20-25

¹⁰ Life expectancy for children with cerebral palsy and mental retardation: Implications for life care planning; Richard T. Katz; Neurorehabilitation, Issue: Volume 18, number3/2003, pages 251-270.

Adaptive behavior is an important and necessary part of the definition and diagnosis of mental retardation. It is the ability to perform daily activities required for personal and social sufficiency. Assessment of adaptive behavior focuses on how well individuals can function and maintain independently and how well they meet personal and social demands. Persons with severe and profound levels of cognitive and adaptive disability typically have additional co-morbid conditions (other medical diagnoses). For example, one in five individuals with mental retardation may also have cerebral palsy, epilepsy or other debilitating conditions. However, two critical co-morbid risk factors include mobility limitations and eating impairments.¹¹ These two risk factors tend to have a significant effect on overall morbidity and mortality. Thus, mobility impairments and the need for special assistance when eating are two risk factors that placed individuals at a higher mortality risk.

Figure 6: Level of Disability and Mortality



The MRDD fatality review process began to look carefully at the presence of these two factors during calendar years 2004 and 2005. As illustrated in Figure 6, of the 70 decedents reviewed over this two-year period, 31, or 44% were classified as profoundly retarded, 16, or 22% were classified as severely retarded, 14, or 20% were classified as moderately retarded, and 9, or 13% were classified as mildly retarded.

Table 16 below presents information on the decedents by level of disability for calendar years 2004 and 2005 and the identified risk factors of feeding and mobility impairments.

- Of the 31 decedents classified as profoundly retarded, 24 had mobility limitations, 12 had feeding impairments, 10 decedents experienced both risk factors, and five decedents had none of the identified risk factors.

¹¹ American Dietetic Association, Providing nutritional services for infants, children and adults with developmental disabilities and special health care needs, May 2003.

- Of the 16 decedents classified as severely retarded, nine had mobility limitations, one had a feeding impairment, one had both risk factors, and six had none of the identified risk factors.
- Of the 14 decedents classified as moderately retarded, six had mobility limitations, two had feeding impairments, and six had none of the identified risk factors. Lastly, of the 12 decedents classified as mildly retarded, three had mobility limitations¹², three had feeding impairments and four decedents had none of the identified risk factors.

Table 16. Level of Disability and Risk Factors for calendar years 2004-2005

Total N=70	Level of Disability		Risk Factors									
	N=36	N=34	Percentage of Population		No Risk Factors Identified		Mobility Limitations		Feeding Impairments		Both Risk Factors	
	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005
Mild	5	4	13%	12%	1	3	2	1	2	1	0	1
Moderate	7	7	20%	21%	3	3	3	3	1	1	0	0
Severe	6	10	17%	29%	2	4	4	5	0	1	0	1
Profound	18	13	50%	38%	3	2	14	10	8	4	7	3

As highlighted in Tables 16 and 17, in line with expected trends, the relationship between level of mental retardation and mortality shows that persons with the most significant disabilities and health care needs (severe and profound, N=47 or, 67%) had a higher rate of mortality during the 2004 and 2005 calendar years. Overall, 48 decedents or 68%, had at least one of the identified risk factors associated with increased mortality. In addition, forty (57%) of the decedents were male, and thirty (43%) of the decedents were female.

¹² Mobility limitations include the use of adaptive equipment, and/or wheelchair dependent.

Table 17: Level of Disability, Gender and Risk Factors 2004-2005 N=70			
Level of Disability	Males N=40	Level of Disability	Females N=30
Profound N=19	Of the 19 male decedents with an Axis II Diagnosis of Profound MR (48%), 15 (80%) had mobility limitations, 8 (42%) had feeding impairments, 6 (32%) had both risk factors and 2 (10%) had no risk factors. Fourteen (74%) of the males were Black and ranged in age from 37 to 70 years, with an average age of 48 years and five males were Caucasian who ranged in age from 51 to 86 years, with an average age of 70 years.	Profound N=12	Of the 12 female decedents with an Axis II Diagnosis of Profound MR (40%), 9 (75%) had mobility limitations, 4 (33%) had feeding impairments, 4 (33%) had both risk factors and 3 (25%) had no risk factors. Ten (84%) females were Black who ranged in age from 22 to 87, with an average age of 58 years and two females were Caucasian who ranged in age from 44 to 82 years, with an average age of 63 years.
Severe N=8	Of the 8 male decedents with an Axis II Diagnosis of Severe MR (20%), four (50%) had mobility limitations, and 4 (50%) had no risk factors. All 8 males were Black who ranged in age from 43 to 73 years, with an average age of 55 years.	Severe N=8	Of the 8 female decedents with an Axis II Diagnosis of Severe MR (27%), six (75%) had mobility limitations, and 2 (25%) had feeding impairments, one had both risk factors and 2 (25%) had no risk factors. Six (75%) of the females were Black who ranged in age from 46 to 64, with an average age of 56 years. Two (25%) of the decedents were Caucasian who ranged in age from 59 to 73 years, with the average age of 66 years.
Moderate N=8	Of the 8 male decedents with an Axis II Diagnosis of Moderate MR (20%), three (37%) had mobility limitations, two (25%) had feeding impairments, and three (37%) had no risk factors. Five (65%) of the males were Black who ranged in age from 40 to 79 years, with an average age 66 years, and three (35%) of the males were Caucasian who ranged in age from 59 to 72 years, with an average age of 64 years.	Moderate N=6	Of the 6 female decedents with an Axis II Diagnosis of Moderate MR (20%), three (50%) had mobility limitations, and three (50%) had no risk factors. All the females were Black who ranged in age from 40 to 90 years, with an average age 66 years.
Mild N=5	Of the 5 male decedents with an Axis II Diagnosis of Mild MR (12%), one (20%) experience mobility limitation, two (40%) had feeding impairments, one (20%) had both risk factors, and three (60%) had no risk factors. Four (80%) of the males were Black who ranged in age from 49 to 75 years with an average of 59 and one (20%) was Caucasian age 56 years.	Mild N=4	Of the 4 female decedents with an Axis II Diagnosis of Mild MR (13%), Two (50%) experience mobility limitations, one (25%) experienced feeding impairments, one (25%) had both risk factors, and two (50%) had no risk factors. All of the females were Black who ranged in age from 23 to 93 years, with an average of 50 years.

- **Manner of Death 2000-2005**

Table 18 provides an overview of the manner of death for the 2000-2005 decedents.

Table 18: Manner of Death

Manner of Death	Number N=184						Total Number & Percentage	
	2000 N=25	2001 N=32	2002 N=26	2003 N=31	2004 N=36	2005 N=34		
Natural	24	28	24	30	34	32	172	94%
Accident	1	3	2	1	1	1	9	5%
Suicide								
Homicide								
Undetermined		1			1			.05%
Pending						1		

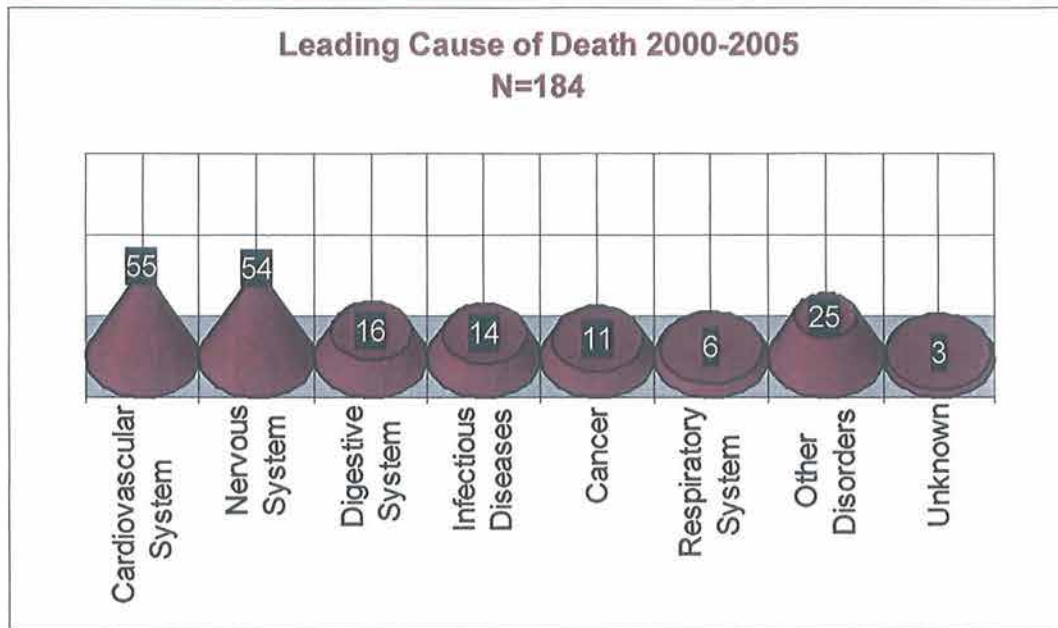
Table 19 below presents information on the leading causes of death for individuals served by MRDDA for calendar years 2000 through 2005.

- **LEADING CAUSE OF DEATH (2000-2005)**

A review of the deceased MRDD population spanning calendar years 2000-2005 revealed that the majority of the decedents succumbed to disorders of the cardiovascular system (N=55 or, 30%). Hypertensive and Arteriosclerotic Cardiovascular Diseases dominated in this group. Disorders of the nervous system, responsible for the disabling illness, followed closely with 54 cases or, about 30%. Ailments of the gastrointestinal system (N=16 or, 9%) and Infectious Diseases (N=14 or, 8%) were the third and fourth causes of death respectively in this population.

Cancer was the fifth leading cause with eleven cases (6%), followed by six cases of Respiratory System Disorders representing three percent. Although only six deaths were due to disorders of the respiratory system, pneumonia and bronchopneumonia, whether or not associated with aspiration of gastric contents, were contributing factors in more than 20% of the cases (N=37).

Figure 7: Leading Causes of Death



Twenty-five cases (14%) were categorized as Other Disorders to include: Blood Diseases, Choking on food material, Diabetes Mellitus, Morbid Obesity, Motor Vehicle Accidents, complications resulting from therapeutic measures, overdose of a therapeutic drug, and an unknown injury. Three cases (2%) were not included in this review. These consumers died out-of-state and it has not been possible to obtain copies of their Death Certificates.

CONCLUSION

By reviewing the information from each death, the FRC hopes to continue the initiation of necessary changes that foster quality provisions for individuals being served by MRDDA. An important outgrowth of this process is the recognition of best practices, and recommendations to implement those practices as systemic changes. The FRC understands that the information submitted for review cannot change the circumstances that led to individual deaths, however, the Committee strives to use the information to identify trends, direct training needs, recommend modification of public and private policies in order to address systemic issues and to improve the quality of life for these citizens of the District.

GLOSSARY OF TERMS

Term	Definition
Age	The length of somebody's or something's existence: the length of time that somebody or something has existed, usually expressed in years
Autopsy Report	A detailed report is prepared consisting of the autopsy procedure, microscopic and laboratory findings, a list of diagnoses, and a summary of the case
Cause of Death	The underlying pathological condition or injury that initiates the chain of events which brings about the demise
CRF	Community Residential Facility for individuals diagnosed with an intellectual disability (MR)
Down Syndrome	One of the most common and readily identifiable chromosomal condition associated with mental retardation and is caused by a chromosomal abnormality
Gender	The sex of a person or organism (male or female), or of a whole category of people or organisms
Group Home	Group Homes for Mentally Retarded Persons are licensed facilities that range in size from four (4) to eight (8) customers
Hospice	A program or facilities that provide special care for people who are near the end of life and for their families
Hospital	An institution where people receive medical, surgical, or psychiatric treatment and nursing care
ICF/MR	A licensed residential facility, which is certified and funded through Title XIX (Medicaid) for consumers diagnosed with an intellectual disability (MR)
IMIU	Incident Management and Investigations Unit for DHS/MRDDA
Leading Cause of Death	The total number of deaths for all ages by cause of death (a percentage is attributed to each age group)
Level of Disability	Individuals with severe to profound cognitive impairment
Life Expectancy	The average expected length of life: the number of years that somebody can be expected to live, according to statistics
Manner of Death	Manner of death refers to the circumstantial events surrounding the death
Mental Retardation	The District of Columbia Code defines mental retardation as a significantly "sub average general intellectual level" determined in accordance with standard measurements as recorded in the Manual of Terminology and Classification in Mental Retardation, 1973

**MRDD Fatality Review Committee
2005 Annual Report/Special Edition**

MRDD FRC	Mental Retardation and Developmental Disabilities Fatality Review Committee
MRDDA	Mental Retardation and Developmental Disabilities Administration
Natural Home	Consumers diagnosed with an intellectual disability (MR) and reside in the home of a parent, family member or independently
Neurologic Conditions	Disorders of the neuromuscular system: The central, peripheral, and autonomic nervous systems, the neuromuscular junction, and muscle
Nursing Home	A long-term healthcare facility that provides full-time care and medical treatment for people who are unable to take care of themselves
OCME	Office of the Chief Medical Examiner
Race	Race is a distinct population of humans distinguished in some way from other humans. The most widely observed races are those based on skin color, facial features, ancestry, genetics, and national origin
Recommendations	A course of action to promote improvement in the delivery of care or services
Retrospective Review	Study and/or report using historical data
Skilled Care	An institution (or a distinct part of an institution) that is primarily engaged in providing skilled nursing care and related services for residents who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons
Specialized Home Care	Specialized Home Care (Foster Homes) is provided by families within a private home living environment for three (3) or less individuals, under a Specialized Home Care
Supervised Apartments	A Supervised Apartment is typically a living arrangement for one to three customers with mental retardation, with drop-in twenty-four hour supervision. Supervised Apartments may be single units grouped in a cluster within an apartment complex, or scattered throughout a complex
Systemic Issues	Affecting the entire system of care and services rendered
Ward	<ol style="list-style-type: none">1 .A city division: an administrative or electoral division of an area such as a city, e.g., Wards 1-8 in the District of Columbia2 Individuals under the custody and care of the District of Columbia.

APPENDICES

GOVERNMENT OF THE DISTRICT OF COLUMBIA

ADMINISTRATIVE ISSUANCE SYSTEM

Mayor's Order 2001-27
February 14, 2001

SUBJECT: Establishment – District of Columbia Mental Retardation and Developmental Disabilities Administration (MRDDA) Fatality Review Committee

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, 87 Stat. 790, Pub. L. No. 93-198, D.C. Code § 1-242(2) (1999 Repl.), it is hereby **ORDERED** as follows:

I. ESTABLISHMENT

There is hereby established in the government of the District of Columbia the "District of Columbia Mental Retardation and Developmental Disabilities Administration (MRDDA) Fatality Review Committee" (hereinafter 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 (DWs) with mental retardation or developmental disability in order to: gather and analyze empirical evidence about fatalities in this population; safeguard and improve the health, safety and welfare of these DWs; reduce the number of preventable deaths; and promote improvement and integration of both the public and private systems serving these vulnerable District residents.

(For the purposes of this Order, a District Ward is an individual committed by a court to the care and custody of the District government, or who is under the supervision or care of the District government or of programs contracted by the District government to deliver such care, for reasons of mental retardation or developmental disability.)

III. DUTIES

- A. Expeditiously review deaths of mentally retarded or developmentally disabled DWs, especially those who reside in group homes, foster homes, nursing homes or any other residential or health care facilities licensed or contracted by the District (see Section X below);
- B. Identify the causes and circumstances contributing to deaths of DWs;

- B. Promulgate recommendations based on the findings of the reviews that support the development and implementation of new or improved services, practices, policies or procedures of the agencies and programs (public or private) that serve these DWs, and that will enhance the protection of the target population; and
- C. By 30 April of each year, produce an annual report that provides information and statistical data obtained from the reviews of deaths that occurred during the previous calendar year. The annual report shall be submitted to the Mayor and made available to the public. The information to be contained in the report shall include, at a minimum:
 - 1. Statistical data on all fatalities of DWs reviewed by the Committee, including numbers reviewed, demographic characteristics of the subjects, and causes and manners of death;
 - 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 which are generated from the reviews, including service enhancements, systemic improvements or reforms, and changes in laws, policies, procedures or practices that would better protect DWs, and could prevent future deaths.

V. COMPOSITION OF THE FATALITY REVIEW COMMITTEE

Members 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 these DWs. The Committee membership shall comprise:

- 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 persons with mental retardation or developmental disabilities;
- D. *Ex officio* members shall include the directors or their designees from the following District government departments or agencies, or their successor programs:

1. Department of Human Services (DHS):
 - a. Mental Retardation and Developmental Disabilities Administration (MRDDA)
 - b. Office of Inspections and Compliance (OIC)
 - c. Rehabilitation Services Administration (RSA)
 - d. Adult Protective Services (APS)
2. Office of the Chief Medical Examiner (OCME)
3. Department of Health (DOH)
 - a. Health Regulation Administration (HRA)
 - b. Medical Assistance Administration (MAA)
 - c. State Center for Health Statistics (SCHS)
 - d. Bureau of Injury and Disability Prevention (BIDP)
4. Metropolitan Police Department (MPD), Criminal Investigations Division
5. Office of the Corporation Counsel (OCC)
6. Office of the Inspector General (OIG)
7. Commission on Mental Health Services (CMHS)
8. Fire Department and Emergency Medical Service, 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 services 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 Mayor's Order establishing this Committee, one-third shall be appointed for 3-year terms, one-third for 2-year terms and one-third for 1-year terms. The date the first members are installed shall become the anniversary date for all subsequent appointments.

- A. A member appointed to fill an un-expired term shall serve for the remainder of that term. Members may continue to serve until re-appointed or replaced. Members may serve not more than two consecutive full terms;
- B. Each member representing a public agency, shall be designated by the director of that department, and shall serve at the pleasure of the Mayor; and
- C. *Ex officio* 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 notifications and information, as well as for the appropriate dissemination of information to the Committee. Some of the responsibilities of the Coordinator, under the direction of the Committee Co-Chairs and with the assistance of Committee members, shall include:

- A. Receive and log in all reports of 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 meetings 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. Serve as the Committee liaison to other fatality review committees.

VIII. AGENCY LIAISONS: ROLES AND RESPONSIBILITIES

Each agency/program shall designate a Committee Liaison to work directly with the Coordinator. This person shall serve as the primary point of contact for that 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 DWs;
- 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 purposes 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; and
 - 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 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 or preparation of the Annual Report.
3. The Committee shall conduct multi-disciplinary reviews of the events and circumstances surrounding the deaths of DWs 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 review shall be conducted.
5. The case review process shall include presentation of the case summary, followed by presentations of relevant information concerning the death by any agencies or persons 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 includes 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 III D 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 DWs, and implementing recommendations made by the Committee. This panel will be responsible for advising the Mayor on the ramifications of the recommendations, and at the Mayor's direction, developing implementation 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.
3. The Advisory Panel shall comprise the directors of relevant District Departments, who shall serve *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)

- (c) Office of the Corporation Counsel (OCC)
- (d) Metropolitan Police Department (MPD)
- (e) Office of the Inspector General (OIG)
- 4. The Panel may also include the following agencies, should they agree to participate:
 - (a) Office of the United States 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 unexplained manners of death (i.e.- homicide, suicide, accident or undetermined), 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. stabbing or cutting wounds
 - 2. Abuse, either physical or sexual
 - 3. Neglect, including medical and custodial
 - 4. Malnourishment or dehydration
 - 5. Circumstances 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 counterparts 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 be limited to:
 - 1. MRDDA
 - 2. Contracted service providers (e.g.-group home staff)

3. OIC
4. OCME
5. MPD
6. OIG
7. OCC
8. DOH

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 Committee Coordinator prior to the review.

Similar written notification shall be provided to all independent and/or community individuals invited 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:

- A. Initial Data Form;

- 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 record 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 inside 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 reports are not public documents and shall be maintained only in the Committee record. Persons who 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 are 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 for ensuring that all information identifying third persons such as witnesses, complainants and agency/institution/program staff or professionals involved with the family are protected against disclosure are:

1. The same procedures established for DWs 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 third persons in materials for distribution.

XV. RECOMMENDATIONS

- A. Draft recommendations shall be developed by the Committee Coordinator based on issues raised during the reviews.
- 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 meetings of the Full Committee.
- C. Final recommendations are incorporated into 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 relating 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 Office of the Chief Medical Examiner. Expenses shall be obligated against funds designated for this 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.


ANTHONY A. WILLIAMS
MAYOR

ATTEST: 
BEVERLY D. RIVERS
SECRETARY OF THE DISTRICT OF COLUMBIA

GOVERNMENT OF THE DISTRICT OF COLUMBIA**ADMINISTRATIVE ISSUANCE SYSTEM**

Mayor's Order 2005-143
September 30, 2005

SUBJECT: Re-establishment – District of Columbia Mental Retardation and
Developmental Disabilities Fatality Review Committee

ORIGINATING AGENCY: Office of the Mayor

By virtue of the authority vested in me as Mayor of the District of Columbia by section 422(2) of the District of Columbia Home Rule Act (Home Rule Act), approved December 24, 1973, 87 Stat. 790, D.C. Official Code § 1-204.22 (2) and (11)(2001), it is hereby **ORDERED** that:

I. RE-ESTABLISHMENT

There is hereby re-established in the Executive branch of the government of the District of Columbia the District of Columbia Mental Retardation and Development Disabilities ("MRDD") Fatality Review Committee (hereinafter referred to as the "Committee").

II. PURPOSE

The Committee shall examine events and circumstances surrounding the deaths of District wards over the age of 18 years with mental retardation or a developmental disability in order to: gather and analyze empirical evidence about fatalities in this population; safeguard and improve the health, safety and welfare of District wards over the age of 18 years with mental retardation or a developmental disability; reduce the number of preventable deaths; and promote improvement and integration of both the public and private systems serving District wards over the age of 18 years with mental retardation or a developmental disability. For purposes of this Mayor's Order, a District ward over the age of 18 years with mental retardation or a developmental disability may be defined as an individual committed by a court to the care and custody of the District government, or who is under the supervision or care of the District government or of programs contracted by the District government to deliver such care, for reasons of mental retardation or developmental disability.

III. DUTIES

The duties of the Committee shall include:

- a. Expeditiously reviewing deaths of District wards over the age of 18 years with mental retardation or a developmental disability, especially those who reside in group homes, foster homes, nursing homes or any other residential or health care facilities licensed or contracted by the District;
- b. Identifying the causes and circumstances contributing to deaths of District wards with mental retardation or a developmental disability;
- c. Reviewing and evaluating services provided by public and private systems that are responsible for protecting or providing services to District wards over the age of 18 years with mental retardation or a developmental disability, and assessing whether said entities have properly carried out their respective duties and responsibilities; and
- d. Based on the results of the reviews (both individual and in the aggregate), identifying strengths and weaknesses in the governmental and private agencies and/or programs that serve District wards over the age of 18 years with mental retardation or a developmental disability and making recommendations to the Mayor and the agencies and programs directly to implement systemic changes to improve services or to rectify deficiencies. The recommendations may address, but are not limited to, proposing statutes, policies or procedures (both new or amendments to existing ones); modifying training for persons who provide services to District wards over the age of 18 years with mental retardation or a developmental disability; enhancing coordination and communication among entities providing or monitoring services for District wards over the age of 18 years with mental retardation or a developmental disability; and facilitating investigations of fatalities.

IV. FUNCTIONS

The functions of the Committee shall include:

- a. Developing and issuing procedures governing its operations within ninety (90) days of the effective date of this Mayor's Order. The procedures shall include, at a minimum, the following:
 1. Methods by which deaths of District wards over the age of 18 years with mental retardation or a developmental disability are identified and reported to ensure expeditious reviews;

2. A process by which fatality cases are screened and selected for review;
 3. A method for ensuring that all information identifying District wards over the age of 18 years with mental retardation or a developmental disability, their families and others associated with the cases or the circumstances surrounding the deaths, including witnesses and complainants, is protected against undue disclosure. This is to ensure that steps are taken to protect the right to privacy of an individual and his or her family in conducting investigations, disseminating information to Committee members, reporting as required by the Mayor's Order, and maintaining case records for the Committee;
 4. A method for gathering individual and cumulative data from the reviews;
 5. A method for reviewing whether recommendations generated by the Committee are being implemented and identifying problems related to obstacles/barriers to implementation; and
 6. A method for evaluating the work of the Committee that takes into account community responses to the deaths of District wards with mental retardation or a developmental disability.
- b. On or about December 31st of each year, producing an annual report that provides information obtained from the reviews of deaths that occurred during the previous calendar year. The annual report shall be submitted to the Mayor and made available to the public. The information to be contained in the report shall include at a minimum:
1. Statistical data on all fatalities of District wards with mental retardation or a developmental disability reviewed by the Committee, including numbers reviewed, demographic characteristics of the subjects, and causes and manners of deaths;
 2. Analyses of the data generated by the reviews, to demonstrate the types of cases reviewed (which may include illustrative case vignettes without identifying information), similarities or patterns of factors causing or contributing to the deaths, and trends (including temporal and geographic); and
 3. Recommendations generated from the reviews, including service enhancements, systemic improvements or reforms, and changes in laws,

policies, procedures or practices that would better protect District wards with mental retardation or a developmental disability and that could prevent future deaths.

V.

COMPOSITION

- a. Members 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 District wards over the age of 18 years with mental retardation or a developmental disability. As such, the composition of the Committee shall reflect medical and clinical professionals from various disciplines who serve consumers with mental retardation or developmental disabilities. An effort shall be made to ensure representation from each geographical ward of the District.
- b. The Committee membership shall consist of:
 1. Five (5) members representing the following District government agencies:
 - A. Metropolitan Police Department, Special Victims Unit;
 - B. Office of the Chief Medical Examiner (OCME);
 - C. Office of the Inspector General (OIG), Medicaid Fraud Unit;
 - D. Department of Human Services (DHS), Mental Retardation and Developmental Disabilities Administration (MRDDA); and
 - E. Fire and Emergency Medical Service Department (FEMSD).
 2. A minimum of six (6) and no more than eight (8) public members from the community who shall not be employees of the District government, up to three (3) of whom shall be clinicians with experience in the evaluation and treatment of persons with mental retardation and developmental disabilities. The public members shall include at least:
 - A. Two (2) faculty members from schools of social work at colleges or universities located in the District;

- B. Two (2) physicians who practice in the District with experience in the evaluation and treatment of persons with mental retardation or developmental disabilities;
- C. One (1) psychiatrist and one (1) psychologist or other mental health professional who is licensed to practice in the District with experience in the evaluation and treatment of persons with mental retardation or developmental disabilities.

VI.

TERMS

- a. Public members appointed to the Committee shall serve for three (3) year terms, except that of the members first appointed, one-half shall be appointed for three (3) year terms and one-half for two (2) year terms. The date on which the first members are installed shall become the anniversary date for all subsequent appointments.
- b. Members appointed to represent District government agencies shall serve only while employed in their official positions and shall serve at the pleasure of the Mayor.
- c. A public member shall not serve more than two (2) consecutive full terms.
- d. A member appointed to fill an unexpired term shall serve for the remainder of that term.
- e. A member may hold over after the member's term expires until reappointed or replaced.
- f. A public member may be excused from a meeting for an emergency reason. A public member who fails to attend three (3) consecutive meetings shall be deemed to be removed from the Committee, and a vacancy created. Such vacancies shall be filled by the Mayor as outlined in section V of this Mayor's Order.
- g. A public member may be removed by the Mayor for personal misconduct, neglect of duty, conflict of interest violations, incompetence, or official misconduct. Prior to removal, the public member shall be given a copy of any charges and an opportunity to respond within 10 business days following receipt of the charges. Upon a review of the charges and the response, the Director of the Office of Boards and Commissions, Executive Office of the Mayor, shall refer the matter to

the Mayor with a recommendation for a final decision or disposition. A public member shall be suspended by the Director of the Office of Boards and Commissions, Executive Office of the Mayor, on behalf of the Mayor, from participating in official matters of the Committee pending the consideration of the charges.

VII. ORGANIZATION

- a. The Mayor shall appoint the Chief Medical Examiner and the Administrator, Mental Retardation and Developmental Disabilities Administration, Department of Human Services, as Co-Chairpersons of the Committee, and they shall serve in these capacities at the pleasure of the Mayor.
- b. The Committee may establish its own bylaws and rules of procedure.

VIII. COMMITTEE COORDINATOR: ROLES AND RESPONSIBILITIES

The Chief Medical Examiner shall appoint a Committee Coordinator who shall serve as the focal point for receiving case notifications and information, as well as for the appropriate dissemination of information to the Committee.

IX. FULL COMMITTEE

- a. A majority of the members shall be present to constitute a quorum.
- b. Meetings of the full Committee shall be held for the purposes of:
 - 1. Conducting case reviews or assessing additional data from prior cases that have since become available;
 - 2. Considering recommendations arising from available case reviews;
 - 3. Preparing an annual report; and
 - 4. Conducting any other business necessary for the Committee to operate or fulfill its duties.

- c. Case review meetings of the full Committee shall be held monthly, if there are cases for review. After procedures have been established and tested, the Committee may consider holding case review meetings every other month (bi-monthly), if practicable. The full Committee may also convene additional meetings as needed for additional case reviews, or for other specific purposes of the Committee, including the development of recommendations or preparation of the annual report.
- d. The Committee shall conduct multi-disciplinary reviews of the events and circumstances surrounding the deaths of District wards over the age of 18 years with mental retardation or a developmental disability as defined in section II, above, in order to provide the data to fulfill the purposes and duties of the Committee as enumerated in sections II and III, respectively.
- e. Case reviews will occur at the first Committee meeting after the Committee receives notification of the fatality, or at the first meeting after sufficient materials are received for conducting the review. The review may be preliminary, pending conclusion of the investigation and prosecution, or release by the prosecutor to conduct the review, at which time a comprehensive review shall be conducted.
- f. The case review process shall include presentation of the case summary, followed by presentations of relevant information concerning the death by any agencies or persons involved with District wards over the age of 18 years with mental retardation or a developmental disability or investigating the event.
- g. Following presentation of the facts, the Committee will discuss the case and any issues that it raises, guided by the following principles and questions:
 - 1. What factors or circumstances caused or contributed to the death? (This may include consideration of social service delivery and coordination to District wards over the age of 18 years with mental retardation or a developmental disability and their families and compliance with, or development of, applicable or needed laws, procedures and regulations.)
 - 2. What responses and investigations resulted from the death? (This includes whether all necessary agencies were notified and responded, and whether any corrective actions were instituted.)

3. Were the services, interventions and investigations concerning the District ward over the age of 18 years with mental retardation or a developmental disability appropriate and adequate for his/her needs? (In other words, did the systems and agencies provide and plan effectively for the District ward over the age of 18 years with mental retardation or a developmental disability?)
 4. Were the staff involved with the District wards over the age of 18 years with mental retardation or a developmental disability adequately prepared, trained, and supported to perform their duties correctly?
 5. Was there adequate communication and coordination among the various entities involved with the District ward over the age of 18 years with mental retardation or a developmental disability?
 6. 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?
- h. Based on the case discussion, the Committee shall formulate applicable recommendations as enumerated above in section III (d) and section IV (a) and (b)(3), for further consideration and possible inclusion in the annual report.

X. SUBPOENA POWER

- a. When necessary for the discharge of its duties, the Committee shall have the authority to issue subpoenas to compel witnesses to appear and testify and to produce books, papers, correspondence, memoranda, documents, or other relevant records. The Mayor hereby delegates the said authority to the Committee, to the extent necessary and appropriate to effectuate the Committee's duties, pursuant to D.C. Official Code §1-301.21(a)(2001).
- b. Except as provided in paragraph (3) of this section, subpoenas shall be served personally upon the witness or his or her designated agent, not less than five (5) business days before the date the witness must appear or the documents must be produced, by one of the following methods, which may be attempted concurrently or successively:

1. By a special process server, at least 18 years of age, designated by the Committee from among the staff of the Committee or any office or organization designated by the Committee; provided, that the special process server is not directly involved in the investigation; or
2. If, after a reasonable attempt, personal service on a witness or witness' agent cannot be obtained, a special process server identified in paragraph (1) may serve a subpoena by registered or certified mail not less than eight (8) business days before the date the witness must appear or the documents must be produced.
3. If a witness who has been personally summoned neglects or refuses to obey the subpoena issued pursuant to this section, the Committee may apply to the Superior Court of the District of Columbia for an order compelling the witness so summoned to obey the subpoena.

XI.

CASE REVIEW CRITERIA AND PROCEDURES

- a. All deaths of District wards over the age of 18 years with mental retardation or a developmental disability shall be reviewed by the Committee.
- b. Factors of particular concern for review include:
 1. All violent or unexplained manners of death (i.e., homicide, suicide, accident or undetermined), which include all deaths caused by injuries, including:
 - A. Fractures;
 - B. Blunt trauma, including fractures;
 - C. Burns;
 - D. Asphyxia or drowning;
 - E. Poisoning or intoxication;
 - F. Gunshot wounds; or
 - G. Stabbing or cutting wounds;

2. Abuse, either physical or sexual;
 3. Neglect, including medical and custodial;
 4. Malnourishment or dehydration; and
 5. Circumstances or events deemed suspicious.
- c. The Committee may, at its discretion, review groups of sudden, unexpected or unexplained deaths of District wards with mental retardation or a developmental disability without regard to age, in order to examine aggregate data in order to address specific issues or trends.
- d. The deaths of District wards over the age of 18 years with mental Retardation or a developmental disability 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 Co-ordinator shall serve as liaison to his or her counterparts in foreign jurisdictions for the purpose of gathering information and obtaining documents (e.g., police or autopsy reports) to complete the review.

XII.

CASE NOTIFICATION PROCEDURES

- a. District agencies and service providers contracted by the District to serve District wards over the age of 18 years with mental retardation or a developmental disability shall provide written notification to the Committee within 24 hours of any death of a District ward over the age of 18 years with mental retardation or a developmental disability, or within 24 hours of becoming aware of such a death. The sources of case notifications will include but are not limited to the:
1. Mental Retardation and Developmental Disabilities Administration (MRDDA), Department of Human Services (DHS);
 2. Contracted service providers (e.g., group home staff);
 3. Office of Inspections and Compliance (OIC), DHS;
 4. Office of the Chief Medical Examiner (OCME);

5. Metropolitan Police Department (MPD);
 6. Office of the Inspector General (OIG);
 7. Office of the Attorney General (OAG);
 8. Department of Health (DOH); and
 9. Department of Mental Health (DMH).
- b. Case notification reports should include for the affected District ward over the age of 18 years with mental retardation or a developmental disability:
1. Demographic data (name, age/date of birth, race, gender);
 2. Address;
 3. Parents/guardians;
 4. Circumstances of the death (date, time, location, activities, risk factors, witnesses or sources of information);
 5. Agencies investigating the death; and
 6. History of the involvement of government agencies or contacted service providers.
- c. MPD, DHS (OIC and MRDDA), DOH and OIG shall provide the Committee copies of all death reports resulting from any investigations that are conducted concerning District wards over the age of 18 years with mental retardation or a developmental disability. The OCME shall provide the Committee copies of all autopsy reports resulting from autopsies and death investigations conducted on District wards over the age of 18 years with mental retardation or a developmental disability. These reports shall be provided within five (5) days after they are completed.

XIII. NOTIFICATION OF PARTICIPANTS

- a. 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 information shall be provided to the Committee Coordinator prior to the review.

- b. Similar written notification shall be provided to all independent and/or community individuals invited to the review meeting. These may include experts from various relevant disciplines or service areas.

XIV. 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 be the following:

1. Initial Data Form;
2. Final Report; and
3. Death Certificate.

XV. 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, consistent with the confidentiality provisions of D.C. Official Code § 7-1305.12 (2001).
- b. Any information gathered in preparation for or divulged during committee reviews shall not be disclosed except as provided in subsection (d) of this section and applicable law, including the Freedom of Information Act, D.C. Official Code § 2-531 *et seq.* (2001).
- c. 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 participant who is not willing to sign a confidentiality statement or to abide by the confidentiality requirements shall not be allowed to participate in case review meetings.

- d. Methods for ensuring that all information identifying third persons such as witnesses, complainants, agency, institution, or program staff or professionals involved with the family are protected against disclosure are:
 - 1. The same procedures established for District wards over the age of 18 years with mental retardation or a developmental disability 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 third persons in materials for distribution.

XVI. RECOMMENDATIONS

- a. Draft recommendations shall be developed by the Committee Coordinator based on issues raised during the reviews.
- b. Draft recommendations shall be distributed to agencies and members for review and comment. Recommendations shall be finalized based on the comments received, including discussion at meetings of the full Committee.
- c. Final recommendations shall be incorporated into the annual report and forwarded to the Mayor. Interim recommendations may be forwarded to the affected entities for expeditious implementation, at the approval of the Committee.
- d. Representatives of agencies, institutions and programs may be invited to full Committee meetings to present their plans for, or progress made towards, implementing the recommendations.

XVII. COMPENSATION

Members of the Committee shall serve without compensation, except that a public member may be reimbursed for expenses incurred in the authorized execution of official Committee functions, if approved in advance by the Chief Medical Examiner or designee, and subject to the appropriation of and the availability of funds.

XVIII. ADMINISTRATION

The Office of the Chief Medical Examiner shall provide administrative support for the Committee, including the services of the Coordinator.

XIX. LEGAL APPLICATION

Nothing in this Mayor's Order shall be deemed to create legal rights or entitlements on the part of District wards over the age of 18 years with mental retardation or a developmental disability, their families, or estates, or to give rise to causes of action prosecutable by said persons.


XX. RECISSIONS

Mayor's Order 2000-82, dated May 30, 2000, and Mayor's Order 2001-27, dated February 14, 2001, are superseded and rescinded in their entirety.

XXI. EFFECTIVE DATE: This Order shall become effective immediately.


ANTHONY A. WILLIAMS
MAYOR

ATTEST:


SHERRYL HOBBS NEWMAN
SECRETARY OF THE DISTRICT OF COLUMBIA

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

Appendix D

Cause of Death of Cases Reviewed in 2005

2003

- 1.* ARDS due to Sepsis due to Aspiration Pneumonia
2. Pulmonary Thromboembolism due to Deep Venous Thrombosis of the Lower Extremities due to Immobility due to Cerebral Palsy and Recurrent Hospitalization for Pneumonia
3. Atherosclerotic Cardiovascular Disease
4. Hypertensive and Atherosclerotic Cardiovascular Disease
5. Pulmonary Postirradiation Fibromatosis following radiation therapy for treatment of breast cancer

2004

6. Seizure Disorder of Undetermined Etiology
7. Hypertensive and Atherosclerotic Cardiovascular Disease
8. Down Syndrome Complicated by Alzheimer's Dementia, Stroke, Pneumonia and Sepsis
9. Non-alcoholic Steatohepatitis due to Obesity
10. Congestive Heart Failure with Bronchopneumonia
11. Cerebellar Intracerebral Hemorrhage due to Hypertensive Cardiovascular Disease
12. Complications following replacement of decannulated gastrostomy tube placed for the treatment of incontinence
13. Sepsis due to Purulent Peritonitis due to Hemorrhagic Cystitis
14. Hypertensive and Atherosclerotic Cardiovascular Disease
15. Sudden Cardiac Death due to Mitral Valve Insufficiency
16. Acute Bronchopneumonia due to Hypertensive Cardiovascular Disease
17. Cardiogenic Shock due to acute Myocardial Infarction due to Atherosclerotic Cardiovascular Disease

2005

18. Carcinoma of the Esophagus, Metastatic
19. Trisomy 21 (Down's Syndrome) and Anoxic Encephalopathy and the complications thereof
20. Bronchopneumonia due to Persistent Vegetative State due to Cerebral Palsy with Spastic Quadriplegia
21. Acute Bronchopneumonia due to Chronic Bronchitis
22. Complications of Right Cerebral Hemisphere Hemorrhage due to Arteriosclerotic Cardiovascular Disease
23. Pulmonary Thromboembolism due to Congestive Heart Failure due to coronary Arteriosclerosis
24. Complications of Cerebral Palsy
25. Hypertensive Cardiovascular Disease

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- 26. Pneumonia Complicating Down Syndrome
- 27. Respiratory Failure due to Down's Syndrome
- 28. Occulsive Saddle Pulmonary Thromboembolus due to Deep Venous Thrombosis due to decreased mobility due to Advanced Chronic Restrictive Lung Disease with Bronchopneumonia
- 29. Ischemic Necrosis of Small Intestine and complications thereof due to Volvulus of jejunum (x2) and Mesenteroaxial Volvulus with compression of Superior Mesenteric Artery due to adhesions from remote Gastrectomy/Esophago-Jejunostomy for Gastric obstruction NOS and recurrent laparotomy for feeding tube placement.
- 30. Respiratory failure due to coagulase Negative Staphylococcus Sepsis due to Bilateral Aspiration Pneumonia due to Esophageal Dysmobility, due to Atherosclerotic and Hypertensive Cardiovascular Disease
- 31.* Sepsis

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

MRDD Fatality Review Committee Recommendations 2000 Through 2005

Appendix E

FRC Recommendation	Status
<ul style="list-style-type: none"> • 01.013 – a) The FRC recommends the need for improvement in case management records, b) and the need for a special budget for MRDDA Wards residing more than twenty (20) miles outside of the District, for special institutional needs. 	a) Pending b) Implemented.
<ul style="list-style-type: none"> • 01.015 - a) The FRC recommends that MRDDA institute a form for medication/dosages to be placed in the front of each District Ward resident. b) The FRC also recommended that a policy be developed to mandate that each District Ward receive annual health and dental assessments 	Implemented.
<ul style="list-style-type: none"> • 01.017 - 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. 	Pending Response.
<ul style="list-style-type: none"> • 01.108 - The FRC recommends for the Committee to develop protocols regarding closure of MRDDA FRC cases. 	Implemented.
<ul style="list-style-type: none"> • 01.019 - 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. 	Implemented. See also Response to Recommendation 03-0147.1.
<ul style="list-style-type: none"> • 01.0172.1 - The FRC recommends that MRDDA develop a partnership with nursing facilities to ensure quality of care. 	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.
<ul style="list-style-type: none"> • 01.0172.2 - 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. 	Implemented.
<ul style="list-style-type: none"> • 02.011 - 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. 	Pending Response.
<ul style="list-style-type: none"> • 02.012 - 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 be denied medical care for life threatening conditions. 	Pending Response.

FRC Recommendation	Status
<ul style="list-style-type: none"> 02.015 – The FRC referred this case to the Quality Council. 	<p>Pending Response. Note: due to the disbanding of the Quality Council MRDDA will request the FRC to review this recommendation and determine whether it should be reissued, considered resolved, or rescinded.</p>
<ul style="list-style-type: none"> 02.021b - The FRC recommends that MRDDA conduct appropriate documentation and supervision [training] to meet the standards of the case management system. 	<p>Implemented.</p>
<ul style="list-style-type: none"> 02.021b - The Committee recommends that some guidelines be put in place at the residential facilities for the care of customer who for whatever reason are not able to participate in their day program. 	<p>Existing ICF/MR regulations, Medicaid Provider agreements and contracts contain standards that govern activities that should 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.</p>
<ul style="list-style-type: none"> 02.024 – The FRC recommended that the Quality Council review the medical records of this customer, and make recommendations to the committee. 	<p>Pending</p>
<ul style="list-style-type: none"> 02.374.3 – The FRC recommends that Adult Protective Service provide education to MRDDA staff and service providers on APS reporting requirements. 	<p>Implemented.</p>
<ul style="list-style-type: none"> 02.0279.1, 03-01471 - 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. 	<p>Completed. Summary Response: 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.</p>
<ul style="list-style-type: none"> 02.028 - The Committee recommended that nursing and group homes 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. 	<p>Implemented.</p>
<ul style="list-style-type: none"> 02.0374.1 - 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. 	<p>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.</p>
<ul style="list-style-type: none"> 02.0374.2 - The FRC recommends that MRDDA develop procedures to address coordination of hospital discharge planning, pain management and follow up of end of life care. 	<p>Pending Response.</p>
<ul style="list-style-type: none"> 02.0569 - The FRC recommends that MRDDA review issues related to transportation of MRDDA clients, including incident reporting and the existence of and follow up to hospital discharge planning. 	<p>Pending Response. Note: Recommendation first issue – 04/29/03; Re-issued to MRDDA 02/23/05.</p>

FRC Recommendation	Status
<ul style="list-style-type: none"> • 02.098 – Following review of this case, the Committee recommended the Quality Trust examine procedures for end-of-life care, including DNR orders and educate providers on appropriate procedures that will maintain the dignity of MRDDA clients. 	Pending Response.
<ul style="list-style-type: none"> • 02.1120.2 – The FRC recommends that the Health Regulation Administration review the records of J.B. Johnson Nursing Home to determine the quality of care that this home provides to MRDDA clients. The committee makes this recommendation due to J.B. Johnson's failure in this case to follow-up on medical issues, identify critical client health care needs, and adequately document the course of care. 	In Progress.
<ul style="list-style-type: none"> • 02.1331.1 - 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. 	Implemented.
<ul style="list-style-type: none"> • 02.3693 - 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. 	Implemented.
<ul style="list-style-type: none"> • 02.3710 - 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. 	Recommendation Declined.
<ul style="list-style-type: none"> • 03.0080 - The FRC recommends that IMIU follow up on the deficiencies of the provider's performance as noted in Mortality Investigation. 	Recommendation Declined.
<ul style="list-style-type: none"> • 03.0100.1 - The FRC recommends that death investigations shall include an interview of the primary care physician when healthcare and communication issues are identified 	The DHS/IMIU Contract Manager for the investigation contract has communicated this recommendation to the contractor. The contractor will be monitored for compliance.
<ul style="list-style-type: none"> • 03.0100.2 - 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. 	MRDDA's Training Division offers comprehensive End of life training to community stakeholders, including those who participate in consumer's IPS teams.
<ul style="list-style-type: none"> • 03.0100.3 - The FRC recommends that the Nursing Board promulgate regulations that establish acceptable ratios of LPN's to ICF-MR facilities. 	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.
<ul style="list-style-type: none"> • 03.0100.4 - 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. 	In Progress.

FRC Recommendation	Status
<ul style="list-style-type: none"> • 03.0122 - 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 reviews and coordinate health care services for all consumers served.</p>
<ul style="list-style-type: none"> • 03.0187.1 - 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. 	<p>MAA Response: "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".</p> <p>Declined by HRA Pending Response from OIG.</p>
<ul style="list-style-type: none"> • 03.0219, 03.0080.2 - 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 	<p>Implemented.</p>
<ul style="list-style-type: none"> • 03.0219.2 - 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 	<p>Implemented.</p>
<ul style="list-style-type: none"> • 03.0278.1 - 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). 	<p>Pending.</p>
<ul style="list-style-type: none"> • 03.0289.1 - 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. 	<p>Implemented.</p>

FRC Recommendation	Status
<ul style="list-style-type: none"> • 03.0289.2 - 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. 	In Progress.
<ul style="list-style-type: none"> • 03.0289.3 – The Office of Corporation Counsel (OCC) and DHS General Counsel should conduct a legal review of the “affidavit of friend”. The research is to address the validity of such documents, and the process in which one becomes an advocate to make medical decisions for MRDDA customers who are receiving services outside of the District of Columbia. 	Response Received. Due to the length of this response from OCC it is available for review via written request to MRDDA FRC Committee.
<ul style="list-style-type: none"> • 03.0379.2 - 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 Response.
<ul style="list-style-type: none"> • 03.0459.1 – The Committee recommends that MRDDA send a letter to providers requiring that they develop an Emergency Medical Care Information Sheet to include: Medications; Clinical Diagnosis list; and Contacts for the purpose of obtaining consent to accompany consumers for routine and emergency medical visits to be left with medical providers. This form should be regularly updated. 	Pending Response.
<ul style="list-style-type: none"> • 04.0190 – The FRC recommends that MRDDA provide training on coordinated services and support for senior (elderly) MRDDA consumers 	Implemented.
<ul style="list-style-type: none"> • 04.0432 - The FRC recommends that OCME investigators should be made aware of medications and other co-existing disorders by DHS/IMIU via the DHS/MRDDA Fatality Review Form 	Pending Response.
<ul style="list-style-type: none"> • 04.0520 - The FRC recommends that MRDDA continue plans for training regarding risk factors and to use the Board of Nursing as experts and support on MRDDA’s efforts. 	Implemented.
<ul style="list-style-type: none"> • 04.0408 - The FRC recommends that all health care issues are incorporated in the ISP in a coordinated plan of care. 	Implemented.
<ul style="list-style-type: none"> • 04.0408.1 - The FRC recommends that MRDDA follow up with the Providers Medical Passport System Review Form 	Implemented.
<ul style="list-style-type: none"> • 04.0531 - The FRC recommends that IMIU investigation report (via Columbus)¹ includes a review of day programs that offer medical support during the day. MRDDA shall provide a list of all Medical Day providers to IMIU 	Pending Response.
<ul style="list-style-type: none"> • 04.0531.1 – Initial Recommendation Dated 11/19/04 – The FRC recommends that this body report the practices of this provider to the Medical Board. <p>Revised Recommendation Dated 01/28/05 - This recommendation is being revised to read: The FRC recommends that MRDDA send a letter to VOCA regarding the practices of this physician with a carbon copy to the Medical Board and OIG.</p>	Pending Response.

¹ The Columbus organization is a contractor with the District of Columbia, Department of Human Services. This organization conducts mortality investigations for deceased persons with mental retardation and developmental disabilities.

FRC Recommendation	Status
<ul style="list-style-type: none"> 04.0531.2 - The FRC recommends that MRDDA send a reminder to the provider community regarding MRDDA's Medical Care Protocols. 	Pending Response.
<ul style="list-style-type: none"> 04-0531 - The FRC recommends that the DHS/IMIU investigation report (via Columbus) include a review of the day programs that offer medical supports during the day. MRDDA shall provide a list of all Medical Day providers to IMIU. 	Implemented
<ul style="list-style-type: none"> 04-531.1 - The FRC recommends that MRDDA report the practices of this physician to [the appropriate agency] with a copy forwarded to the Medical Board and the OIG. 	Pending
<ul style="list-style-type: none"> 04-531.2 - The FRC recommends that MRDDA send a reminder to the provider community regarding MRDDA's Medical Care Protocols. 	Implemented
<ul style="list-style-type: none"> 04-0750 - The Fatality Review Committee recommends that DHS/IMIU educate the Columbus Investigative Group on District of Columbia laws and policies regarding DNR and End of Life issues. 	Implemented
<ul style="list-style-type: none"> 04-0750.1 - The Fatality Review Committee recommends that MRDDA ensure that at a minimum, persons with complex medical issues, terminal illnesses and/or other significant medical compromise have a legal guardian appointed to act in their best interest and assist in making major life/end of life decision when the consumer is without family or guardians. This process should be reinforced in the ISP. 	Pending
<ul style="list-style-type: none"> 04-0750.2 - The Fatality Review Committee recommends that DHS/IMIU shall request the Columbus Investigative Group record the diagnoses according to the DMS IV TR. 	Implemented
<ul style="list-style-type: none"> 04-0214 - DHS/IMIU shall review the Child Fatality Review Committee's (CFRC) protocols for developing a consumer-centered mortality review. 	Reviewed Completed
<ul style="list-style-type: none"> 04-0720 - DHS/IMIU shall education/inform the Columbus Investigative Group of Quality Trust's role in relationship to the appointment of advocates. 	Implemented
<ul style="list-style-type: none"> 05-0111 - MRDDA needs to develop policies/standards that define their expectations of providers as related to health care. 	Implemented
<ul style="list-style-type: none"> 05-adm1 - The FRC requests DHS to prepare and present a plan to manage the seven (7) outstanding 2002 investigations of non-class members. 	Pending
<ul style="list-style-type: none"> 05-0382 - MRDDA should ensure that providers train and conduct competency-based reviews of staff, consultants, volunteers, etc., regarding health care coordination of consumers. 	Implemented
<ul style="list-style-type: none"> 05-0455 - MRDDA should review the 199 high-risk customers to ensure the appointment of medical guardians and specify the medical issue(s). 	Pending
<ul style="list-style-type: none"> 05-0455.1 - MRDDA case managers should be trained on the ISP process to ensure documentation is being followed through successfully. 	Pending
<ul style="list-style-type: none"> 05-0657 - MRDDA should invite the staff of the Office of the Attorney General (OAG) to provide mandatory training on capacity and guardianship for at-risk consumers. 	Implemented

FRC Recommendation	Status
<ul style="list-style-type: none">• 05-0657.1 - MRDDA should initiate and lead discussions with authorities, agencies and stakeholders regarding contractual arrangements with primary care physicians.	Pending

ACKNOWLEDGEMENT

We wish to acknowledge the dedication and unwavering support of the public servants, private agency/program representatives, university, and community volunteers who serve as members of the District of Columbia Mental Retardation and Developmental Disabilities Fatality Review Committee. It is an act of courage to acknowledge that the deaths of individuals diagnosed with mental retardation and other developmental disabilities is a community problem. The willingness of Committee members to step outside of their traditional professional roles and examine all the circumstances that may have contributed to these deaths and to seriously consider ways to improve the quality of life and to prevent future fatalities is an admirable and difficult challenge. This challenge speaks to the commitment of members to improving services and truly making life better for the residents of this city. Without this level of dedication, the work of the Committee would not be possible.

We would like to thank the members of the Committee for volunteering your time, giving of your resources, support and dedication to achieving our common goal. A special thanks is extended to the community volunteers and educators who continue to serve the citizens of the District throughout every aspect of the fatality review process.



This document was prepared by the Office of the Chief Medical Examiner,
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