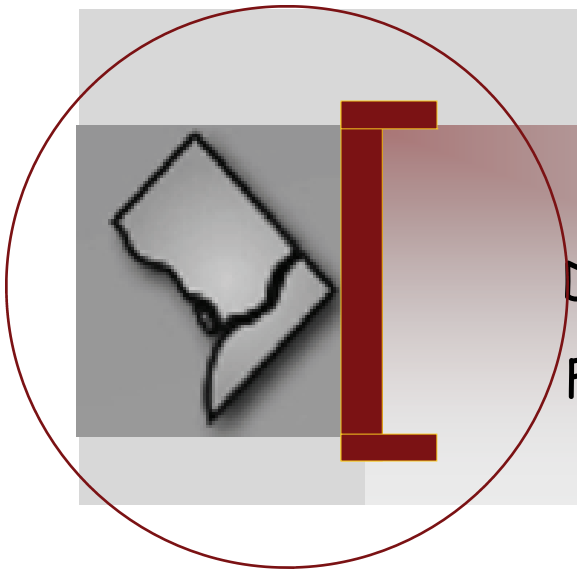

District of Columbia Developmental Disabilities Fatality Review Committee

2010 Annual Report

The Honorable Vincent Gray, Mayor
District of Columbia Government

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

District of Columbia
Developmental Disabilities
Fatality Review Committee

2010 Annual Report

Mission:

To reduce the number of preventable deaths of individuals with mental retardation and developmental disabilities through identifying, evaluating and improving programs and systems responsible for protecting and serving citizens

Presented To:
The Honorable Vincent Gray, Mayor, District of Columbia
The Council of the District of Columbia

May 2012

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EXECUTIVE SUMMARY

The District of Columbia Developmental Disabilities Fatality Review Committee (hereinafter known as the "DD FRC" or the "Committee") is pleased to present its tenth Annual Report. The DD FRC was initially established as the Mental Retardation and Developmental Disabilities Administration (MRDDA) FRC in February 2001, by Mayor's Order 2001-27, and re-established in September of 2009 by Mayor's Order 2009-225 (see Appendix A). The Committee is charged with examining the events surrounding the deaths of individuals 18 years of age and older who were receiving services from the District of Columbia Department on Disabilities Services (DDS) at the time of death.

KEY DD FRC DATA FINDINGS

TOTAL FATALITIES IDENTIFIED IN 2010 (N=35)

During calendar year 2010, a total of 35 of the 2,026 consumers served by the Department on Disability Services (DDS) died

- In 2010, a total of 35 deaths were identified as meeting the DD FRC criteria for review.
- The largest number of DDS consumer deaths in 2010 involved decedents over the age of 60 years.
- The majority of the decedents were male.
- The leading manner of death was Natural followed by Accidents.

FINDINGS FROM DEATHS REVIEWED IN 2010 (N=30)

During 2010, the Committee reviewed 30 deaths of DDS consumers who died between calendar years 2007 through 2010. The following is a summary of the data included in the 2010 Annual Report.

- In the cases reviewed, 14 were classified as having severe intellectual disabilities; 6 were classified as having profound or moderate intellectual disabilities; and 4 were classified as having mild intellectual disabilities.
- Of the 30 deaths reviewed, 25 were attributed to Natural causes.
- Fifteen of the decedents were over the age of 60 years.
- Seventeen of the deaths reviewed were female recipients of DDS services.
- Of the 30 deaths reviewed, 22 were Black/African American decedents.
- Of the deaths reviewed, 21 of the decedents died in a hospital setting.
- Of the deaths reviewed, 26 involved decedents who resided in the District of Columbia; the majority resided in Wards Five (N=7) and Four (N=6).

DD FRC RECOMMENDATIONS FROM 2010 CASES REVIEWED

Based on the 30 cases reviewed during calendar year 2010, the DD FRC issued recommendations to District Government agencies that related to improved health care, case management, improved emergency response and case monitoring (see *Section III*: DD FRC 2010 Recommendations).

INTRODUCTION

> *"Never doubt that a small group of thoughtful, committed citizens can Change the World. Indeed, it's the only thing that ever has."*
>
> Margaret Meade

The 2010 Annual Report is a summary of the work performed by the Developmental Disabilities Fatality Review Committee (DD FRC) during calendar year 2010. It provides a synopsis of the total population identified by the Committee annually as meeting the criteria for review and the data that is specific to the 30 deaths reviewed during calendar year 2010.

The DD FRC was re-established in September 2009, 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 and residents 18 years of age and older who received services and/or supports from DDS. One goal of the DD FRC is to make recommendations to improve care and service delivery to citizens of the District.

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

One of the primary functions of the DD FRC involves the collection, review, and analysis of DDS consumer death-related data in order to identify consistent patterns and trends that assist in increasing knowledge related to risk factors and guiding system change/enhancements. The fatality review process includes the examination of an independent investigative report of each customer's death that includes a summary of the forensic autopsy report; the consumer's social history (including family and caregiver relationships); living conditions prior to death; medical diagnosis and medical history; and services provided by DDS and its contractors. It also includes the assessment of agency policies and practices and compliance with District laws and regulations and national standards of care. Many reviews result in the identification of systemic problems and gaps in services that may impact the consumer's quality of life. Another important result of this process is the recognition of best practices, and recommendations to create and institutionalize these practices as a critical component of systemic change.

SECTION I: TOTAL MORTALITY FINDINGS

This report addresses the circumstances surrounding the deaths of District residents diagnosed with an intellectual disability and are consumers of the Department on Disability Services (DDS). Eligibility criteria used by DDS to identify persons with intellectual disabilities are as follows:

- Psychological evaluations, based on one or more standardized tests), that document significantly sub average general intellectual functioning (Intelligence Quotient ("IQ") scores of 69 or below), and was diagnosed and/or manifested before the age of 18
- Psychological evaluation(s) that include a formal assessment of adaptive behavior or other supporting documentation of adaptive behavior functioning manifested during the developmental period and reports that indicate that the disability existed concurrently with a full scale IQ of 69 or below and reports that indicate that the disability continues to adversely impact the individual's life after the age of 18 and
- Psychological and psychiatric evaluations that document any diagnosed psychiatric condition, should one be present (current and historical)

Section I of this Report provides a general overview of decedent demographics for the deaths that occurred during calendar years 2001 through 2010 and determined to meet the criteria for review by the DD FRC.

Table 1 below illustrates the total number of consumers served by DDS for a ten year period, the total number of consumer deaths annually, and the trend related to the percentage of DDS clients who died during this past decade. During calendar years 2001 through 2010, the number of consumers served ranged from 1,547 to 2,026 (Endnote 1, see page 15), while the number of DDS deaths during the same ten year span ranged from 27 to 36 annually.

Table 1: District of Columbia DDS Population and Deaths 2001 to 2010

Year	*Population*	*Number of Deaths*	*Percentage*
2010	2026	35	1.7%
2009	1946	29	1.5%
2008	1994	27	1.4%
2007	2018	30	1.5%
2006	1974	30	1.5%
2005	1993	34	1.7%
2004	1915	36	1.9%
2003	1790	31	1.7%
2002	1703	26	1.5%
2001	1547	32	2.0%

Table 2: Status of Deaths Identified and Review By Calendar Year			
Year	*# Deaths Identified By Year*	*# Deaths Reviewed By Year*	*# Deaths Pending Review*
2010	35	30	5
2009	29	25	4
2008	27	27	0
2007	30	21	9
2006	30	23	7
2005	34	24	10
2004	36	26	10
2003	31	23	8
2002	26	21	5
2001	32	32	0

Table 2 summarizes the deaths identified as meeting the DDS FRC criteria for review by calendar years since the Committee's inception. Of the 310 deaths identified, 252 were reviewed and 58 were pending review as of December 31, 2010.

Demographic Decedent Data - Total Mortality Population Identified

Age of Decedents

Based on cases reviewed, the relationship between age and mortality has historically demonstrated the mortality rate increasing as DDS consumers begin to age (see Figure 1). Annually the majority of the deaths reviewed have involved DDS consumers who were in the age group of 61 years of age or older. Overall, this trend among the DDS population has remained constant since the inception of the fatality review process in 2001. Additionally, the trend among the DDS population is also consistent with the expected national trend of mortality increasing with age for the broader population.

Figure 1: Age DDS FRC Decedents by Year

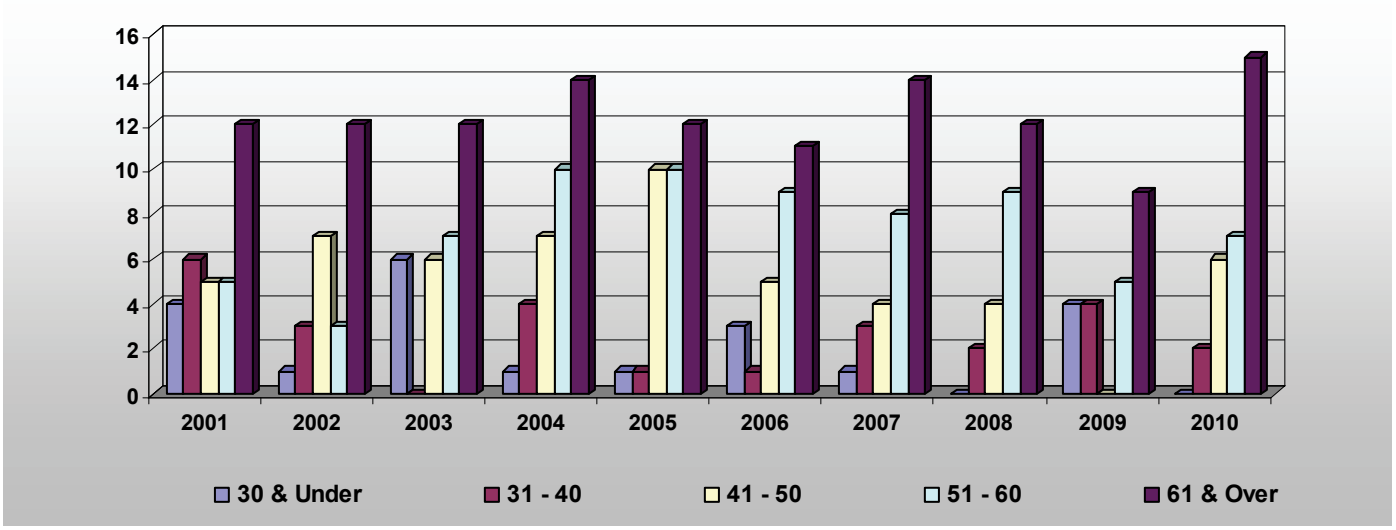
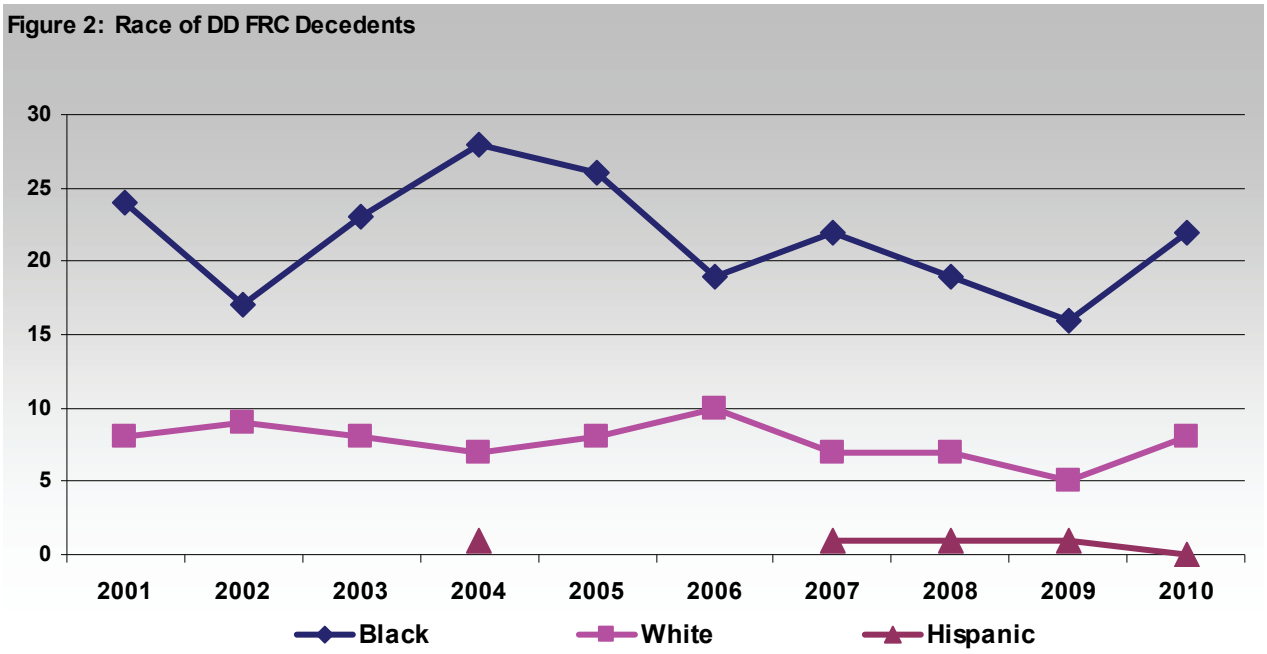


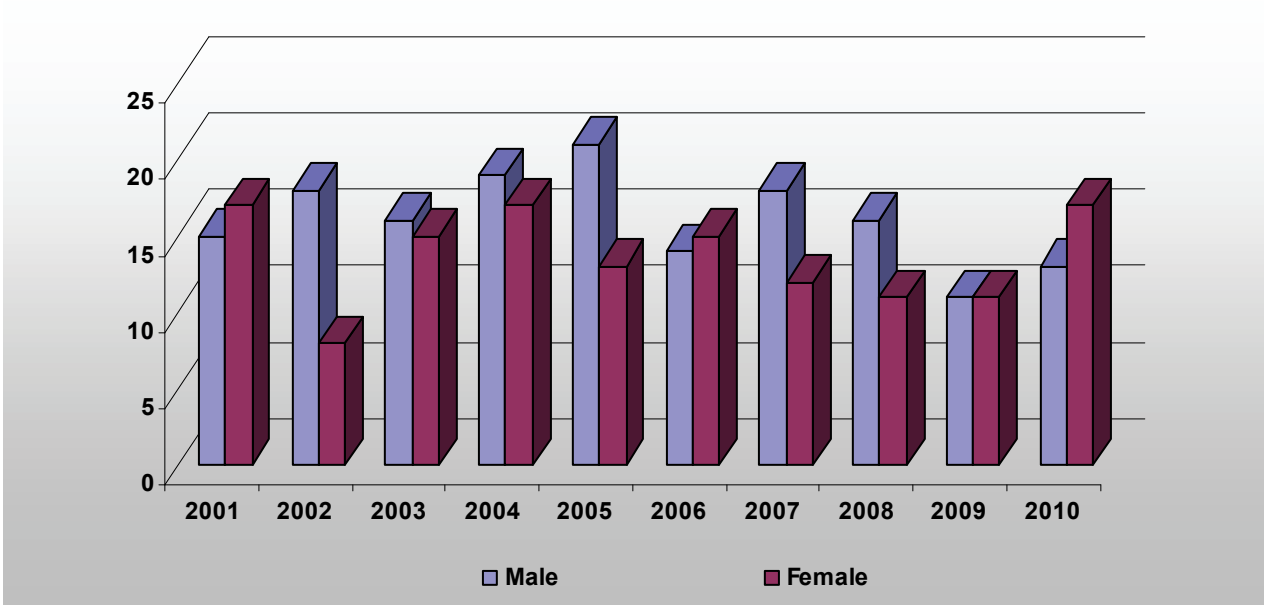
Figure 2: Race of DD FRC Decedents



Race and Gender of Decedents

Consistent with the overall DDS population, the majority of the DD FRC deaths reviewed involved Black/African American decedents. Within the past decade, 216 of the 297 DD FRC decedents were male.

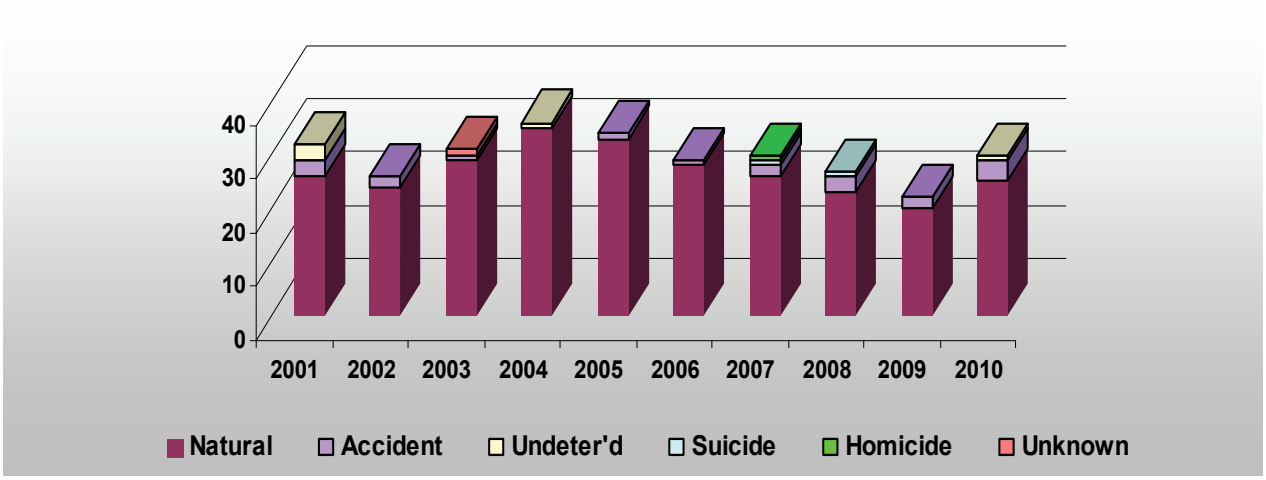
Figure 3: DD FRC Decedent Gender



Manner of Death – Total Deaths Identified

Historically, the leading manner of death for DD FRC cases was Natural. Since the inception of this Committee, 269 DDS consumers died of natural causes. During this ten year span, 19 consumers died of Accidental causes. There was one Homicide in 2007 and two Suicide deaths—one occurring in 2007 and the other in 2008. Of the Undetermined deaths there were three in 2001, one in 2004 and 2010.

Figure 4: DD FRC Decedent 2001-2010



Section II: Summary of 2010 Case Review Findings

During calendar year 2010, the DD FRC reviewed the deaths of 30 consumers diagnosed with intellectual and developmental disabilities who received services through the Department on Disability Services. These reviews were limited to deaths that occurred between 2007 and 2010. The majority involved 19 fatalities that occurred in 2009. Section II will cover the data and findings that resulted from the 30 cases reviewed.

Age/Gender and Motality

The ages of the 30 decedents whose deaths were reviewed ranged from 32 to 90 years of age; the average age was 61 years of age. As Figure 5 illustrates, 15 (50%) of the 30 cases reviewed involved DDS consumers over the age of 60 years of age. There were seven consumers between the ages of 51 and 60 years of age and six between 40 and 50 years of age. Of the 30 deaths reviewed none of the consumers were younger than 32 years old. Of the 30 deaths reviewed, there were 17 female and 13 male decedents.

Figure 5: 2010 DD FRC Decedents

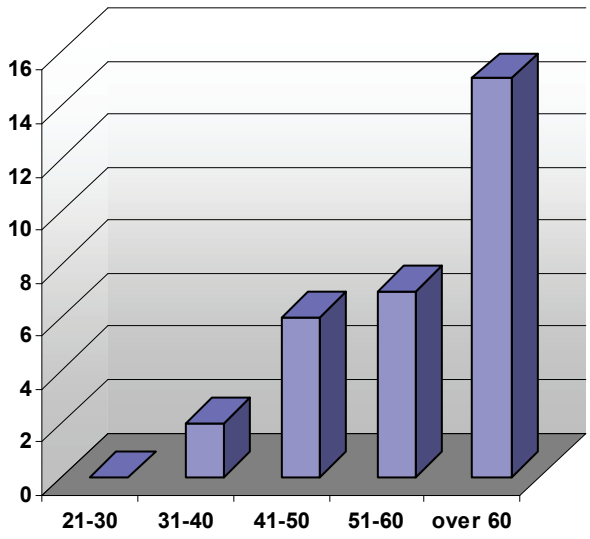


Table 3 depicts the age ranges of the decedents by gender and year of death for the 30 cases reviewed during 2010. The 30 deaths that occurred in 2010 involved 13 male and 17 female decedents, both of which covered all age ranges.

Table 3: Age and Gender By Year of Death (N = 30 Cases Reviewed)

Age	*Male*	*Female*
Under 41	**1**	**1**
41 – 50	**2**	**4**
51 – 60	**4**	**3**
61 & Over	**6**	**9**

Race and Mortality

Consistent with previous FRC review years and the overall DDS population served, the majority of the deaths reviewed in 2010 were Black/African American decedents. Twenty-two of the 30 decedents were Black/African American, and 8 were Caucasians.

Table 4: Race and Gender of 2010 DDS Decedents

Race	*Male*	*Female*
Black	**10**	**12**
Caucasian	**3**	**5**
Other	**0**	**0**

Table 4 illustrates the race by gender and year of death of the 2010 cases reviewed. Of the 30 deaths that occurred in 2010, 13 of the decedents were male, and 17 of the decedents were female.

Place of Residence

The 30 deaths reviewed involved consumers who resided in their natural homes, foster homes/group homes, Intermediate Care Facilities (ICF), nursing homes, and supportive living environments. Thirteen of the 2010 DD FRC consumers resided in Intermediate Care Facilities where they received 24 hour care. Eight consumers resided in supportive living environments where they received individualized Medicaid Waiver services. Five consumers resided in their natural home, and were receiving individualized Medicaid Waiver services.

Table 5: 2010 DD FRC Decedent Place of Residence

Place of Residence	*2010 N=30*
Natural Home	**5**
Nursing Home	**1**
Foster Home	**1**
Supportive Living	**8**
Intermediate Care Facility	**13**
Residential Rehabilitation	**2**

Location of Death

Table 6: 2010 DD FRC Decedent Place of Death

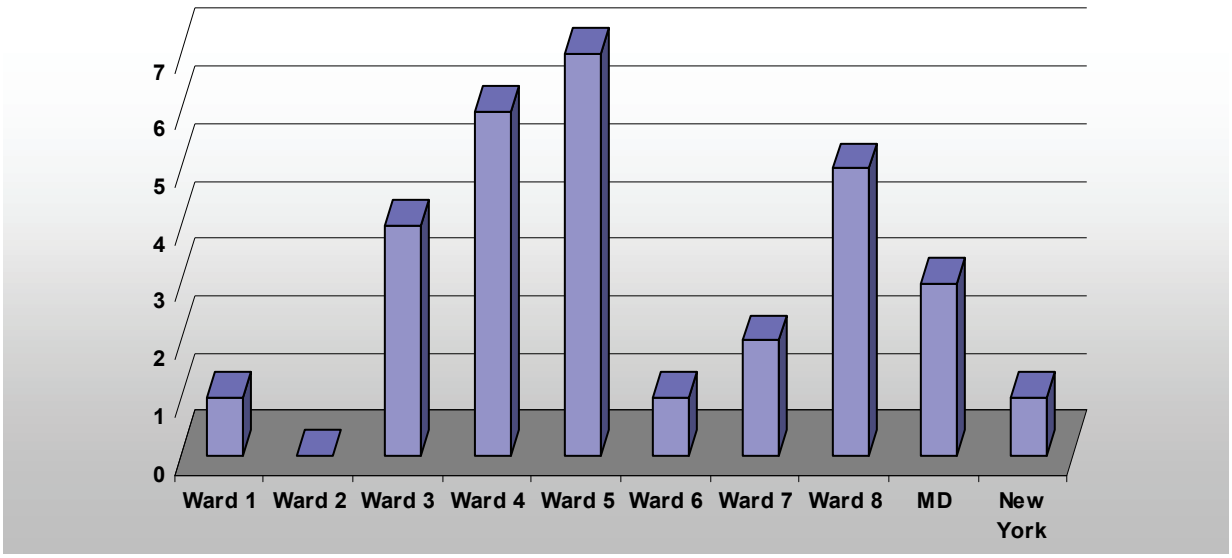
Place of Death	*2010(N=30)*
Hospital	**21**
Nursing Home	**2**
Intermediate Care Facility (ICF)	**2**
Private Home	**5**

The case reviews revealed the deaths occurred in locations that included hospitals, nursing homes, Intermediate Care Facilities and the consumer's natural home. As depicted in Table 6, 21 of the 2010 DD FRC decedents died while in a hospital setting. Five of consumers died in their private home. The remaining consumers died in a nursing facility (2), or Intermediate Care Facility (2). Fourteen consumers received individualized Medicaid Waiver services in their home setting.

Ward of Residence

Ward of residence refers to the DDS consumer's residential address at the time of the fatal event. As illustrated in Figure 6, 26 of the consumer's resided in the District of Columbia. Of these, the majority resided in Wards Five (7) and Four (6). Three consumers resided in Maryland, and one consumer resided in New York.

Figure 6: 2010 DD FRC Decedent Ward of Residence



Mobility and Feeding Impairments

Mobility and feeding impairments are recognized problems that place individuals at higher risk of morbidity and mortality. The independent investigative reports provided to the DD FRC provide detailed information related to these risks and the Committee considers these factors as part of the case evaluation process. Based on the 30 deaths reviewed, seven involved consumers who used wheelchairs; and five functioned with support (i.e., leg braces, walker, cane, etc.). Four of the consumers had a gastronomy tube in place for assistance with feeding. Of the 30 cases reviewed, 19 of the consumers were independent with their feeding abilities and 17 were able to ambulate without supports.

Table 7: Feeding and Mobility

Feeding Method		*Mobility*	
G-Tube	4	Wheelchair	7
With Assistance	7	Bedridden	1
Independent	19	With support	5
		Without support	17

Neuropsychiatric Disorders

Table 8 provides a numerical summary of Axis I and Axis II of the Multi-axial Diagnostic System, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR). Axis I reports clinical disorders and other conditions that may be a focus of clinical attention. Axis II reports mental retardation and personality disorders. Mental Retardation is distinguished by level of severity in cognitive functioning and adaptive functioning. When significant neurological dysfunction is associated with other organ system anomalies, an individual's life expectancy may be shortened. It is not uncommon that severity of cognitive impairment is correlated to other health risks.

Table 8: Neuropsychiatric Disorders by Axis

Axis I Disorders Identified in DDS Decedents		*Axis II Mental Retardation Level of Severity*	*Cognitive (N = 30)*	*Adaptive (N= 30)**
Bipolar Disorder with Psychotic features	**1**	**Profound**	**6**	**13**
Dementia	**4**	**Severe**	**14**	**9**
Depressive Disorder	**5**	**Moderate**	**6**	**6**
Impulse Control Disorder, NOS	**6**	**Mild**	**4**	**2**
Seasonal Affective Disorder	**1**			
Schizophrenia	**5**			

Cause and Manner of Death

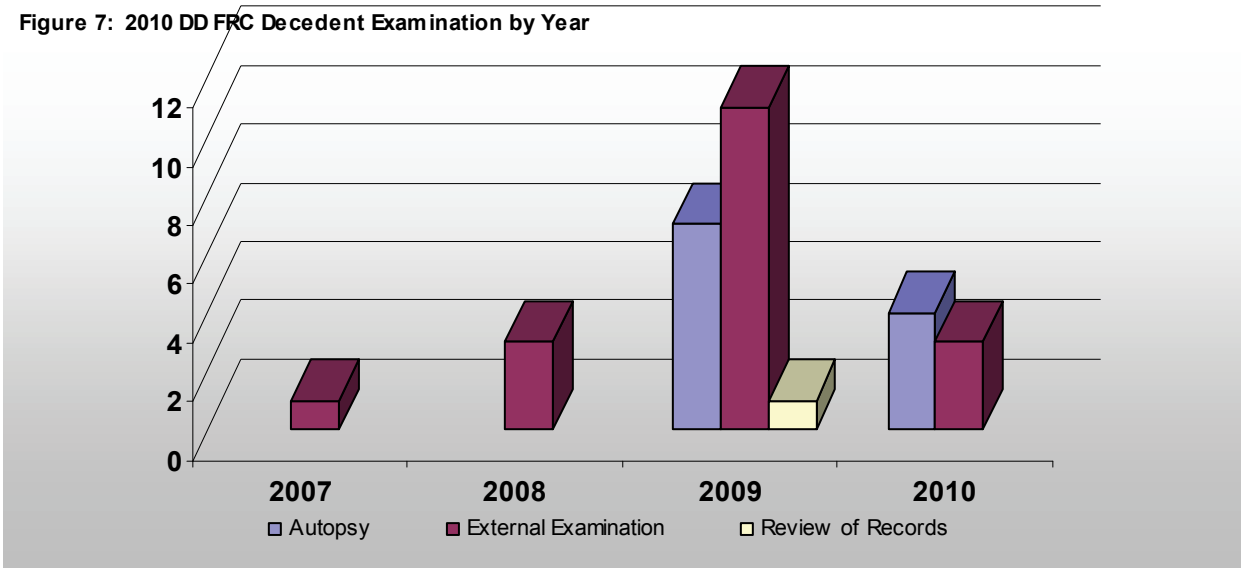
Mayor's Order 2006-123, "Autopsies of Deceased Clients of the Mental Retardation and Developmental Disability Administration", requires the Office of the Chief Medical Examiner to perform the appropriate physical examination (autopsy, or external examination) on all persons with mental retardation or developmental disability who received services from the Department on Disabilities Services. Of the 30 cases reviewed in 2010, 11 decedents received autopsies; and 18 had an external examination. In one case, the medical examiner reviewed the medical records of a decedent whose death occurred outside of the District of Columbia.

Manner of Death

The manner of death, as determined by the forensic pathologist, is an opinion based on the known medical and investigatory facts concerning the circumstances leading to and surrounding the death, in conjunction with the findings at autopsy and laboratory tests. Consistent with previous years, the majority of the 30 deaths reviewed in 2010 were determined to be Natural

deaths (N=25). There were four deaths that were Accidents, and one Undetermined manner of death.

Figure 7: 2010 DD FRC Decedent Examination by Year



Cause of Death

Table 9 provides a list of the causes of death associated the 30 deaths reviewed during 2010. Nine resulted from disorders of the Cardiovascular System, mainly Hypertension and Arteriosclerosis. The second leading cause of death was Cancer, as observed in five cases. Other natural causes include Viral/Bacterial Infection, Respiratory Infection, Sepsis, Gastrointestinal Disorders, Neurological Disorders, and Hepatic Disease. Two of the Accidental deaths were the result of Asphyxia (aspiration of food).

Table 9: Causes of Death - 2010 Deaths Reviewed

Causes of Death	*# of Deaths (N=30)*
Cardiovascular System Disorder	**9**
Respiratory Infection	**3**
Cancer	**5**
Gastrointestinal System	**1**
Hepatic Disease	**1**
Asphyxia	**2**
Blunt Injury	**1**
Sepsis	**3**
Viral/Bacterial Infection	**4**
Neurological Disorder	**1**

Section III:

DD FRC Recommendations for the 2010 Review Year

SECTION III: DD FRC 2010 RECOMMENDATIONS

During calendar year 2010, the DD FRC issued the following recommendations based on the review of 30 cases:

FRC Recommendation	*Status*
OCME will share with DDS factors underlying reasons for external examination rather than autopsy in determining causes of death for decedents.	Dr. Pierre-Louis (Chief Medical Examiner) gave a presentation at the MRDDA/FRU meeting on August 17, 2010. The presentation addressed the Mission and Function of OCME and included a discussion on what determines whether an autopsy is internal or external. DDA staff and Liberty Healthcare (new Investigation contractor) were in attendance.
OCME and DDS will work together to gather better clinical information to help in deciding whether an autopsy rather than an external examination is conducted to determine cause of death.	DDS has provided all the requested information to OCME to help in the decision making of whether a autopsy or external examination is needed.
DDS should ensure the management of psychotropic medications is consistent with generally accepted practices that include: a) Clearly defined psychiatric diagnoses that are not mutually exclusive and are based on accepted based on clinical criteria; b) The avoidance of polypharmacy (inter-and intra-class); c) The lowest possible dosages and appropriate titrations; d) Avoidance of long term use of benzodiazepines; e) Comprehensive psychiatric monitoring to include documentation of diagnostic concerns, medical issues, mental status examination, discussion of side effects, or psychosocial concerns affecting behavior, and documentation of vegetative symptoms when indicated.	DDS will file the sign in sheet and the Human Rights meeting minutes in the individual's files to ensure a meeting is being held and that the medications are being monitored by a Psychiatrist

DD FRC 2010 Recommendations Continued

FRC Recommendation	*Status*
DDS will ensure that Wholistic Inc. responds to Columbus recommendations	DDS sent these recommendation to the provider on 12/1/09 and requested a plan of correction which the provider sent on 12/17/09. The Quality Improvement Specialist reviewed the plan of correction and closed the issues on 12/30/09. The Quality Improvement Specialist monitors the plan of correction until all issues are corrected. DDS Service Coordinators will continue to monitor the continued compliance during monthly visits and monitoring reviews.
DDS should ensure Health Management Care Plan contain realistic and measurable goals for identified health issues and management procedures (interventions) are individualized and preventative in nature.	DDS will ensure all individuals being served by DDS have a HMCP that addresses the specific needs of the each person. DDS Service Coordinators will review the HCMP for each person DDS supports to ensure the HCMP is specific to the individual. All of the individual's medical issues should be written on the HCMP and the medical intervention needed specified. DDS Service Coordinator along with the Health and Wellness nurse assigned to the providers will conduct monitoring of all HCMP to ensure they contain the needed information. A new HMCP will be written if the current one does not meet the DDS Health and Wellness Standards. Comple-
DDS should offer/provide training and best practice guidelines on End of Life Planning to ensure planning is timely and in keeping with accepted medical, legal and ethical criteria	DDS will continue to develop partnerships to provide end of life training on an ongoing basis. DDS will explore training used by other states on End of Life training. DDS will consult with the provider community as well as the Georgetown Partnership and the Quality Trust to develop best practice standards for End of Life training. DDS provides mandatory End of Life training for all staff. DDS will continue to provide End of Life training for staff to ensure all individuals being served by DDS have an End of Life Plan should they desire one. This plan will be developed with the individual and their team..
DDS should continue to provide training on end of life planning to ensure planning is timely and in keeping with accepted medical, legal and ethical criteria.	DDS has added End of Life training to required training for all DDS Service Coordinators. All service coordinators must annually, complete End of Life Training

DD FRC 2010 Recommendations Continued

FRC Recommendation	*Status*
DDS should ensure the residential provider implements the following recommendation: • Careco should implement the use of a skin integrity • assessment tool (i.e. the Braden Scale assessment) on individuals deemed at risk. • Careco should document the treatment of skin integrity problems to include wound measurements and staging, also appropriate consultation with a nutritionist. • Careco should implement a policy and training around pain management and assessment. • Careco should implement a policy for the use of PRN medications that mandate a nursing assessment prior to their administration as well as strict limitation on their use with stated parameters advising staff when to notify the nurse or physician. • Careco should ensure that for health care problems (such as constipation) identified on the HCMP, the records should include documentation on what treatment was provided and an analysis of associated risks (i.e. chronic constipation, and records of bowel habits).	DDS sent these recommendation to the provider on 12/1/09 and requested a plan of correction which the provider sent on 12/5/09. The Quality Improvement Specialist reviewed the plan of correction and closed the issues on 12/30/09. DDS Quality Improvement Specialist reviewed the plan of correction submitted by the provider on 12/9/09, to ensure the provider was implementing the plan of correction as it was written. The Quality Improvement Specialist monitors the plan of correction until all issues are corrected. DDS Quality Improvement Specialist reviewed the plan of correction submitted by the provider on 12/9/09, to ensure the provider was implementing the plan of correction as it was written. The Quality Improvement Specialist monitors the plan of correction until all issues are corrected. The provider in this case will make the changes suggested and they will provide optimal care to all the individuals they serve. DDS Service Coordinators will continue to monitor the continued compliance during monthly visits and monitoring.
DDS should develop a process to ensure that record requests are complied with by hospitals.	DDS will explore using the FRC subpoena power to ensure hospitals comply with record requests in a timely manner. DDS legal department is researching the FRC subpoena power rules. DDS Mortality Review Coordinator continues to develop working relationships with area hospital staff to ensure requests are being sent timely. The DDS Mortality Review Coordinator has started tracking record request weekly with complete follow up phone calls and letters to medical records directors as needed. DDS will be able to provide the death investigation company with a complete file from the hospitals to ensure all records are available for review.
DDS should encourage Service Coordinators to clearly document follow up of identified problems/issues through resolution.	All identified issues are entered in the Alert Resolution System and are monitored until they are closed. The issues must go through 3 levels of resolution until the issue is closed. The Service Coordinator is required to record all progress toward the resolution of an issue. Once the Service Coordinator has completed all the work resolving an issue, his or her supervisor must review the Service Coordinator's work before the issue can be closed in the system.

DD FRC 2010 Recommendations Continued

FRC Recommendation	*Status*
DDS should ensure that all pertinent records and documentation is promptly available for review after an individuals' death. In order to be able to offer greater insight and detailed feedback, it is important that the most recent records are available. This is especially important if the individual died in the hospital.	According to DDS MRC Policy, the provider has 5 days to turn all their records over to DDS following a death of an individual. The MRC Coordinator verbally requests these records during his visit to the facility to complete the MRC Death Investigation form. DDS MRC Coordinator follow this up with an email to the Provider agency director requesting all of the decedents records. DDS is also exploring subpoenaing the medical records from hospitals to ensure all records are available for review by the investigation company.

ENDNOTES

Endnote # 1 (Page 2)	Information on the total consumer population was provided by the Department of Disability Services.

APPENDICES

GOVERNMENT OF THE DISTRICT OF COLUMBIA

ADMINISTRATIVE ISSUANCE SYSTEM

Mayor's Order 2009-225
December 22, 2009

SUBJECT: Revitalization –District of Columbia 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"), as amended, 87 Stat. 790, Pub. L. No. 93-198, D.C. Official Code § 1-204.22(2) and (11) (2001), it is hereby **ORDERED** that:

I. ESTABLISHMENT

There is hereby revitalized in the Executive Branch of the government of the District of Columbia the District of Columbia Development Disabilities ("DD") Fatality Review Committee (hereinafter referred to as the "Committee").

II. PURPOSE

The Committee shall examine events and circumstances surrounding the deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying 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 residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability; reduce the number of preventable deaths; and promote improvement and integration of both the public and private systems serving District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability. For purposes of this Mayor's Order, "District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability" may be defined as an individual who is committed by a court to the care and custody of the District of Columbia Department on Disability Services ("DDS"), or who meets DDS eligibility requirements for voluntary admission and is admitted by a court to receive services, or is under the supervision of DDS or of a program contracted by DDS to deliver such services, for reasons of an intellectual disability and/or a qualifying developmental disability. The phrase "District residents over the age of 18 years with an intellectual and/or qualifying developmental disability" is intended to include persons who are committed to the care and custody of the District or its residential providers in accordance with the Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978 (Mentally Retarded Citizens Act), effective March 3, 1979, D.C. Law 2-137, D.C. Official Code § 7-1301.01 *et seq.* (2008 Repl. and 2009 Supp.), and therefore includes "wards of the District of Columbia government" under section 2906 (b) (7) of the Fiscal Year 2001 Budget

Support Act of 2000, effective October 19, 2000, D.C. Law 13-172, D.C. Official Code § 5-1405 (b) (7) (2009 Supp.).

III. DUTIES

The duties of the Committee shall include:

A. Expeditiously reviewing deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability, especially those receiving services who reside in group homes, host homes, supervised living, natural homes or nursing homes or any other residential or health care facilities certified, licensed or contracted by the District;

B. Identifying the causes and circumstances contributing to deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability;

C. Reviewing and evaluating services provided by public and private systems that are responsible for protecting or providing services to District residents over the age of 18 years with an intellectual disability and/or a qualifying 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 residents over the age of 18 years with an intellectual disability and/or a qualifying 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 residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability; enhancing coordination and communication among entities providing or monitoring services for District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability; and facilitating investigations of fatalities, providers of service or individual medical and allied health practitioners.

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. To the extent such procedures already have been developed, issued and implemented the Committee may continue to operate under those procedures. The procedures shall include, at a minimum, the following:

1. Methods by which deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying 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 residents over the age of 18 years with an intellectual disability and/or a qualifying 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 residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability.

B. On or about December 30th of each year, beginning in 2010, 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 residents over the age of 18 with an intellectual disability and/or a qualifying 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 residents over the age of 18 years with an intellectual disability and/or a qualifying 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 individuals with an intellectual disability or a developmental disability. As such, the composition of the Committee shall reflect medical and clinical professionals from various disciplines who serve consumers with an intellectual disability or developmental disabilities, and persons representing the advocacy community. All newly appointed Committee members shall be District residents.

B. The Committee membership shall consist of:

1. Ten (10) members representing the following District government agencies:

    a. Metropolitan Police Department, Special Victims Unit;
    b. Office of the Chief Medical Examiner;
    c. Office of the Inspector General, Medicaid Fraud Control Unit;
    d. Department on Disability Services, Developmental Disabilities Administration;
    e. Department of Human Services;
    f. Department of Mental Health;
    g. Department of Health, Health Regulation and Licensing Administration;
    h. Department of Health Care Finance;
    i. Office of the Attorney General; and
    j. Fire and Emergency Medical Services Department.

2. A minimum of five (5) public members from the community who shall not be employees of the District government, and up to three (3) of whom shall be clinicians with experience in the area of evaluation, treatment and/or support of persons with an intellectual disability or developmental disability. Based on availability, the public members may include at least:

    a. One (1) faculty member from a school of Social Work at a college or university located in the District;
    b. One (1) physician who practices in the District with experience in the evaluation and treatment of persons with an intellectual disability or developmental disability;
    c. One (1) psychiatrist, psychologist or mental health professional who is licensed to practice in the District with experience in the evaluation and treatment of persons with an intellectual disability or developmental disability; and
    d. One (1) member of the community, who has an intellectual disability, is a family member of a person with an intellectual disability or who works for an organization that advocates for those with intellectual disabilities in the District.

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 may be reappointed for a minimum of two (2) full terms based on the approval of the Mayor.

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, in accordance to the composition 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 ten (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 DDS Deputy Director for the Developmental Disabilities Administration, or the functional equivalent, as Co-Chairpersons of the Committee and they shall serve in these capacities at the pleasure of the Mayor.

B. The Chief Medical Examiner shall appoint staff support who shall serve as the focal point for planning and coordinating the major activities and responsibilities of the Committee and disseminating information to and on behalf of the Committee.

C. The Committee may establish its own bylaws and rules of procedures.

VIII. FULL COMMITTEE

A. Twenty-five (25) percent of the members shall be present at the Committee case review meetings 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.

IX. 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 section 3 (a) of the Independent Personnel Systems Implementation Act of 1980, effective September 26, 1980, D.C. Law 3-109, D.C. Official Code § 1-301.21(a) (2006 Repl.).

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's 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.

X. CASE REVIEW CRITERIA AND PROCEURES

A. Case Review Criteria

The Committee shall review the following deaths:

1. All deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability shall be reviewed by the Committee. Factors of particular concern for review include:

   a. All violent or sudden/unexplained manners of death (*i.e.*, homicide, suicide, accident or undetermined), which include all deaths caused by injuries or illness, including but not limited to:
      i. Fractures;
      ii. Blunt trauma;
      iii. Burns;
      iv. Asphyxia or drowning;
      v. Poisoning or intoxication;
      vi. Gunshot wounds;
      vii. Stabbing or cutting wounds;
      viii. Falls;
      ix. Sepsis;
      x. Gastrointestinal blockages; or
      xi. Seizures.

   b. Abuse, either physical or sexual;

   c. Neglect, including medical and custodial;

   d. Malnourishment or dehydration; and

   e. Circumstances or events deemed suspicious.

2. The Committee may, at its discretion, review groups of sudden, unexpected or unexplained deaths of District residents with an intellectual disability and/or a

qualifying developmental disability without regard to age, in order to examine aggregate data to address specific issues or trends.

3. The deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability who live in facilities, homes or other living arrangements outside of the District, or who die outside of 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 Coordinating Staff shall serve as a 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.

B. Case Review Procedures

1. Case review meetings shall be multi-disciplinary and shall occur within three months of receiving the mortality/fatality report or other sufficient materials required to examine the events and circumstances surrounding the death and to fulfill the purposes and duties of the Committee as enumerated in Sections II and III of this Order. 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.

2. The case review process shall include presentation of the mortality investigative report, and may include presentations of relevant information concerning the death by any agencies or persons involved with the decedent or that are investigating the event.

3. Following presentation of the facts, the Committee will discuss the case and any issues highlighted, guided by the following principles and questions:
   a. What factors or circumstances caused or contributed to the death? (This may include consideration of social service delivery and coordination to the decedent and his/her family and compliance with, or development of, 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 decedent appropriate and adequate for his/her needs? (In other words, did the systems, agencies and health care community provide and plan effectively?)
   d. Were the staff involved with the decedent adequately prepared, trained, and supported to perform their duties correctly?
   e. Was there adequate communication and coordination among the various entities involved with the decedent? Are the applicable statutes, regulations, policies and procedures adequate to serve the needs of the target population? If not, what changes are needed?

4. 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.

XI. CASE NOTIFICATION PROCEDURES

A. District agencies and service providers contracted by the District to serve District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability shall provide written notification to the Committee within twenty-four (24) hours of any death of a District resident over the age of 18 years with an intellectual disability and/or a qualifying developmental disability, or within twenty-four (24) hours of becoming aware of such a death. The sources of notifications will include but are not limited to the:

1. Department on Disability Services (DDS), Developmental Disabilities Administration (DDA);
2. Office of the Chief Medical Examiner (OCME);
3. Metropolitan Police Department (MPD);
4. Office of the Attorney General (OAG);
5. Department of Health (DOH); and
6. Department of Health Care Finance (DHCF).

B. Case notification reports should include:

1. Demographic data (*i.e.* name, age/date of birth, race, gender);
2. Address;
3. Parent/guardian;
4. Circumstances of the death (*i.e.* date, time, location, activities, risk factors, witnesses or sources of information); and
5. Agencies investigating the death.

C. MPD, DDS, DOH and DHCF shall provide the Committee copies of all death reports resulting from any investigations that are conducted concerning the population covered by the Order (*see* Section X: Case Review Criteria). The OCME shall provide the Committee with a copy of all autopsy reports resulting from autopsies and death investigations conducted for District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability. These reports shall be provided within five (5) days after they are completed.

XII. 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 staff support 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.

XIII. RECORDS

All records and reports shall be maintained in a secured area with locked file cabinets. One (1) year 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:

A. Final Report; and

B. Death Certificate.

XIV. CONFIDENTIALITY

A. A key tenet of the Committee is the necessity for keeping confidential information obtained by, presented to and considered by the Committee, consistent with the confidentiality provisions of section 512 of the Mentally Retarded Citizens Act (D.C. Official Code § 7-1305.12) (2008 Repl.).

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 of 1976, effective March 29, 1977, D.C. Law 1-96, D.C. Official Code § 2-531 *et seq.* (2006 Repl.).

C. All participants in the Committee proceedings shall be required to sign a confidentiality statement prior to all Committee case review meetings and prior to general meetings where any specific case is discussed. Case-specific information distributed during any 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 or general 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 residents over the age of 18 years with an intellectual disability and/or a qualifying 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.

XV. RECOMMENDATIONS

A. Draft recommendations shall be developed during case review meetings based on issues raised during specific deaths or trends documented from numerous deaths reviewed.

B. Draft recommendations shall be redistributed for finalization and adoption based on consensus of the Committee during subsequent case review meetings prior to transmission to relevant agencies.

C. Final recommendations shall be transmitted to relevant agencies and the Office of the City Administrator and/or Mayor within thirty (30) days of finalization/adoption with request for response within sixty (60) days of receipt. Final adopted recommendations shall also be incorporated into the annual report.

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.

XVI. 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.

XVII. ADMINISTRATION

The Office of the Chief Medical Examiner shall provide administrative support and legal counsel for the Committee.

XVIII. LEGAL APPLICATION

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

XIX. RESCISSIONS

Mayor's Order 2005-143, dated September 30, 2005, is superseded and rescinded in its entirety.

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

ADRIAN M. FENTY
MAYOR

ATTEST:
STEPHANIE D. SCOTT
SECRETARY OF THE DISTRICT OF COLUMBIA

GLOSSARY OF TERMS

TERMS	*DEFINITIONS*
Autopsy Report	A detailed report consisting of the autopsy procedure, microscopic and laboratory findings, a list of diagnoses, and a summary of the case.
CRF/MR	Community Residential Facility for individuals diagnosed with an intellectual disability (MR)
Group Home	Licensed homes for persons with mental retardation that range in size from four (4) to eight (8) customers
Hospice	A program or facility that provides special care for people who are near the end of life and for their families
ICF/MR	A licensed residential facility certified and funded through Title XIX (Medicaid) for consumers diagnosed with an intellectual disability (MR). Consumers receive 24 hour skilled supervised care.
Level of Disability	Cognitive and adaptive impairment ranging from mild to profound
Life Expectancy	The average expected length of life; the number of years somebody is expected to live
Medicaid Waiver	Provides rehabilitative, behavioral, and medical supports to individuals with intellectual and developmental disabilities in residential community , and private home settings.
Natural Home	Consumers residing in the home of a parent, family members or independently
Neurological Conditions	Disorders of the neuromuscular system (the central, peripheral, and autonomic nervous systems, the neuromuscular junction, and muscles)
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
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	A private home living environment for three (3) or less individuals (also includes foster care)
Supervised Apartments	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
Ward	An administrative or electoral division of an area/city, e.g., Wards 1-8 in the District or Individuals under the custody and care of the District of Columbia

CAUSES OF DEATH - 2010 DD FRC DEATHS REVIEWED

Deaths Reviewed that Occurred in 2007:

Age/Race Sex	*Cause of Death*	*Manner of Death*
86/Wht/Female	Congestive Heart Failure due to Hypertensive and Arteriosclerotic Cardiovascular Disease	Natural

Deaths Reviewed that Occurred in 2008:

Age/Race Sex	*Cause of Death*	*Manner of Death*
88/Blk/Male	Arteriosclerotic Cardiovascular Disease	Natural
77/Wht/Female	Complications of Aspiration Pneumonia due to Down's Syndrome	Natural
32/Blk/Female	Septic Shock complicating infection of G-Tube placed for the treatment of Cerebral Palsy, Mental Retardation, and Seizure Disorder	Natural

Deaths Reviewed that Occurred in 2009:

Age/Race Sex	*Cause of Death*	*Manner of Death*
74/Blk/Female	Congestive Heart Failure due to Hypertensive Cardiovascular Disease	Natural
61/Blk/Female	Hypertensive Cardiovascular Disease	Natural
52/Wht/Female	Interstitial Pneumonia due to Microencephaly and Ulegyria of unknown etiology	Natural
49/Blk/Female	Complications of Hypertensive Cardiovascular Disease	Natural
38/Blk/Male	Acute Bronchopneumonia Complicating Blunt Impact of Neck with Paraplegia	Accident
60/Blk/Male	Hypovolemia due to GI Bleed	Natural
44/Blk/Female	Pulmonary Thromboembolism due to Lower Extremity Deep Venous Thrombosis associated with Left Lower Leg Injury Sustained in Fall	Accident
84/Blk/Male	Complications of Bacteremia due to Infected Decubitus Ulcer (s)	Natural
69/Wht/Female	Acute Pulmonary Embolism due to Venous Thrombosis	Natural
56/Blk/Male	Hepatocellular Carcinoma	Natural
60/Blk/Female	Hepatorenal Syndrome due to Primary Bilary Cirrhosis	Natural
63/Blk/Female	Complications of Urinary Tract Infection with Hematuria due to Multiple Renal Calculi	Natural
64/Wht/Male	Urosepsis	Natural
53/Wht/Male	Pneumonia due to Advanced Alzheimer's Disease Associated with Down Syndrome	Natural
49/Blk/Female	Complication of Microencephaly	Natural
61/Blk/Female	Left Pleural Empyema due to Pseudomonas Species and Citrobacter Freundii Infection in Community Acquired Bacterial Pneumonia	Natural

CAUSES OF DEATH - 2010 DD FRC DEATHS REVIEWED

Deaths Reviewed that occurred in 2009 Cont'd.:

Age/Race Sex	*Cause of Death*	*Manner of Death*
78/Blk/Male	Complications of Metastasis Carcinoma of Rectum	Natural
57/Blk/Female	Toxic Epidermal Necrolysis due to Septic Shock due to Multiorgan Failure due to Disseminated Intravascular Coagulation	Natural
90/Wht/Female	Hypertensive and Arteriosclerotic Cardiovascular Disease	Natural

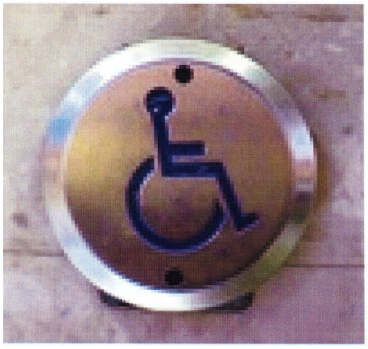
Deaths Reviewed that occurred in 2010:

71/Wht/Male	Complications of Left Femur Fracture	Undetermined
41/Blk/Male	Complications of Non-Hodgkin's Lymphoma	Natural
41/Blk/Female	Asphyxia due to Aspiration of Bolus of Food	Accident
55/Blk/Male	Acute Ischemic Enterocolitis, Undetermined Etiology	Natural
61/Blk/Male	Anoxic Encephalopathy Due to Asphyxia with Cardiopulmonary Arrest Following Obstruction of Airway due to Aspiration of Food	Accident
44/Blk/Male	Non-Hodgkin Lymphoma	Natural
65/Blk/Female	Complications of Multiple Myeloma	Natural

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 Developmental Disabilities Fatality Review Committee. The willingness of Committee members to step outside of their traditional professional roles to examine the circumstances that may have contributed to these deaths and to seriously consider ways to improve the quality of life and prevent future fatalities is an admirable and difficult challenge. This challenge speaks to the commitment of members to our goal of improving services and 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 thank you 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.



Government of the District of Columbia
Office of the Chief Medical Examiner,
Fatality Review Unit
Developmental Disabilities Fatality Review Committee
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