2009 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
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 ninth 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 2009 (N=29)

During calendar year 2009, a total of 29 of the 1,946 consumers served by the Department on Disability Services died.

♦ In 2009, a total of 29 deaths were identified as meeting the DD FRC criteria for review.
♦ The largest number of DDS consumer deaths in 2009 involved decedents over the age of 60 years.
♦ The majority of the decedents were male.
♦ The leading manner of death was Natural followed by Accidental deaths.

FINDINGS FROM DEATHS REVIEWED IN 2009 (N = 22)

During 2009, the Committee reviewed 22 deaths of DDS consumers who died during calendar years 2007 and 2008. The following is a summary of the data included in this 2009 Annual Report.

♦ In the cases reviewed there were 11 consumers diagnosed as having profound mental disabilities; one was diagnosed as having severe mental disabilities; and five each were diagnosed as having moderate or mild disabilities.
♦ Of the 22 deaths reviewed, 20 were attributed to Natural causes.
♦ Nine of the decedents were over the age of 60 years.
♦ Eleven male and Eleven female deaths were reviewed in 2009.
♦ Of the 22 deaths reviewed, 16 were Black/African American decedents.
♦ Of the deaths reviewed, 12 decedents died in a hospital setting.
♦ Of the deaths reviewed, 18 involved decedents who resided in the District of Columbia; the majority resided in Wards Four (N=11) and Seven (N=3).

DD FRC RECOMMENDATIONS FROM 2009 CASES REVIEWED

Based on the 22 cases reviewed during calendar year 2009, the DD FRC issued recommendations to DDS and other appropriate agencies that related to improved health care, health case management, improved emergency response, and case monitoring (see Section III: DD FRC 2009 Recommendations). The recommendations are related to policy and clinical practice.
The 2009 Annual Report is a summary of the work performed by the Developmental Disabilities Fatality Review Committee (DD FRC) during calendar year 2009. 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 22 deaths reviewed during calendar year 2009.

DD FRC (formerly the MRDD 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 the Department on Disability Services. One goal of the DD FRC is to make recommendations to improve care and service delivery to he citizens of the District receiving disability services.

Committee membership is broad, representing a range of disciplines from 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 issues 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 consumer’s death that includes a summary of the forensic autopsy report; the decedent’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 consumers’ 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 that have died during this period. During the calendar year of 2009, DDS served a total of 1,946 consumers. As Table 1 illustrates, the percentage of DDS clients who died between 2001 and 2009 range from 2% to 1.4% of the total number of consumers served annually.

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>Number of Deaths</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>1946</td>
<td>29</td>
<td>1.5%</td>
</tr>
<tr>
<td>2008</td>
<td>1994</td>
<td>27</td>
<td>1.4%</td>
</tr>
<tr>
<td>2007</td>
<td>2018</td>
<td>30</td>
<td>1.5%</td>
</tr>
<tr>
<td>2006</td>
<td>1974</td>
<td>30</td>
<td>1.5%</td>
</tr>
<tr>
<td>2005</td>
<td>1993</td>
<td>34</td>
<td>1.7%</td>
</tr>
<tr>
<td>2004</td>
<td>1915</td>
<td>36</td>
<td>1.9%</td>
</tr>
<tr>
<td>2003</td>
<td>1790</td>
<td>31</td>
<td>1.7%</td>
</tr>
<tr>
<td>2002</td>
<td>1703</td>
<td>26</td>
<td>1.5%</td>
</tr>
<tr>
<td>2001</td>
<td>1547</td>
<td>32</td>
<td>2.0%</td>
</tr>
</tbody>
</table>
Table 2 below summarizes the status of the 275 deaths identified as meeting the DD FRC criteria for review by calendar years since the Committee’s inception. Of the 275 deaths identified since 2001, 219 were reviewed by the DD FRC. As of December 31, 2009, 56 cases were pending review.

<table>
<thead>
<tr>
<th>Year</th>
<th># Deaths Identified By Year</th>
<th># Deaths Reviewed By Year</th>
<th># Deaths Pending Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>29</td>
<td>22</td>
<td>7</td>
</tr>
<tr>
<td>2008</td>
<td>27</td>
<td>27</td>
<td>0</td>
</tr>
<tr>
<td>2007</td>
<td>30</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>2006</td>
<td>30</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>2005</td>
<td>34</td>
<td>24</td>
<td>10</td>
</tr>
<tr>
<td>2004</td>
<td>36</td>
<td>26</td>
<td>10</td>
</tr>
<tr>
<td>2003</td>
<td>31</td>
<td>23</td>
<td>8</td>
</tr>
<tr>
<td>2002</td>
<td>26</td>
<td>21</td>
<td>5</td>
</tr>
<tr>
<td>2001</td>
<td>32</td>
<td>32</td>
<td>0</td>
</tr>
</tbody>
</table>

**DEMOGRAPHIC DECEDENT DATA - TOTAL MORTALITY POPULATION IDENTIFIED**

**Age of Decedents**

Based on the cases reviewed by the DD FRC, 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: DD FRC Decedent Age by Year**
Consistent with the overall DDS population, the majority of the DD FRC reviewed deaths involved Black/African American decedents. Between 2001 through 2009, the Black/African American decedent population ranged from 65% to 78%.

During the nine year reporting period, DDS FRC male decedents outnumber DDS female decedents by 10%. In 2009, the number of both male and female decedents were the same (N=11).

Figure 2: Race of DD FRC Decedents

Figure 3: Gender of DD FRC Decedents
MANNER OF DEATH – TOTAL DEATHS IDENTIFIED

Historically, the leading manner of death for DD FRC cases was Natural. Since the inception of this Committee, Natural deaths have represented from 81% to 97% of the total fatalities identified annually. The second leading manner of death is Accident. Accidental deaths of DDS consumers have occurred in every calendar year with the exception of 2004. During this eight year span, there was one Homicide in 2007 and two Suicide deaths, one occurred in 2007 and the other in 2008; of the Undetermined deaths there were three in 2001 and one in 2004.

SECTION II: SUMMARY OF 2009 CASE REVIEW FINDINGS

During calendar year 2009, the DD FRC reviewed the deaths of 22 consumers diagnosed with intellectual and developmental disabilities served by DDS. These reviews were limited to deaths that occurred in 2007 and 2008 that involved 20 fatalities that occurred in 2008. Section II will cover the data and findings that resulted from the 22 cases reviewed.

AGE/GENDER AND MORTALITY

The ages of the 22 decedents whose deaths were reviewed ranged from 21 to 94 years of age; the average age was 53 years. As Figure 5 illustrates, 14 of the 22 cases reviewed involved DDS consumers over the age of 50 years. There were four decedents between the ages of 21 and 30 years, and four between 31 and 40 years.
Table 3 depicts the age ranges of the decedents by gender and year of death for the 22 cases reviewed during 2009. The 22 deaths that occurred in 2009 involved 11 male and 11 female decedents. Of the 22 deaths reviewed that occurred in 2009, there were no males or females in the 41-50 age category.

### Race and Mortality

Consistent with previous FRC review years and the overall DDS population served, the majority of the deaths reviewed in 2009 were Black/African American decedents. Seventy-three percent or 16 of the 22 decedents were Black/African American, and 5 or 23% were Caucasians. One of the 2009 DD FRC decedents was a Hispanic male.

### Place of Residence

The 22 deaths reviewed involved decedents who resided in their natural homes, Intermediate Care Facilities (ICF), nursing homes and supportive living environments. Seven of the 2009 DD FRC decedents received 24 hour skilled care through an ICF. Eight of

<table>
<thead>
<tr>
<th>Place of Residence</th>
<th>2009 N=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural Home</td>
<td>4</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>4</td>
</tr>
<tr>
<td>Supportive Living Environment</td>
<td>3</td>
</tr>
<tr>
<td>ICF</td>
<td>7</td>
</tr>
<tr>
<td>Residential Rehabilitation</td>
<td>4</td>
</tr>
</tbody>
</table>
the decedents received individualized Medicaid Waiver services in their living environment.

**WARD OF RESIDENCE**

Ward of residence refers to the decedent’s residential address at the time of the death. Figure 7 illustrates the decedents’ District Ward or State of residence at the time of death. Of the 22 deaths reviewed, 18 of the decedents resided either in their natural home, ICF, Nursing home, or supportive living environment located within the District of Columbia. The greatest number of decedents reviewed resided in Wards Four (N=11) and Seven (N=3). Of the 22 deaths reviewed, 3 decedents resided in nursing facilities in Maryland.

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>2009 (N=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>12</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>7</td>
</tr>
<tr>
<td>Private Home</td>
<td>3</td>
</tr>
</tbody>
</table>

**LOCATION OF DEATH**

In the case reviews of the 22 DDS FRC decedents, records indicate the fatal events occurred in locations that included hospitals, nursing homes, and the decedent’s private home. As Shown in Table 5, 12 of the decedents died following admission to a hospital. Seven decedents died in a nursing facility, and the remaining 3 decedents died in their natural home.
MOBILITY AND FEEDING IMPAIRMENTS

Mobility and feeding impairments are recognized problems that place individuals at higher risk of morbidity and mortality. Historically, DD FRC data supports the fact that individuals who require special assistance with ambulating and feeding have a greater risk of death. The independent mortality reports reviewed by 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 22 deaths reviewed, six involved decedents who used wheelchairs; and four functioned with support (i.e., leg braces, walker, cane, etc.). Ten of the cases reviewed involved decedents who were completely mobile and were able to function without support. Fifty-four percent of the decedents were independent in their feeding needs.

NEUROPSYCHIATRIC DISORDERS

Table 7 below 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 is for reporting clinical disorders and other conditions that may be a focus of clinical attention. This includes reporting of 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 level of severity in cognitive functioning and adaptive functioning. When significant neurological dysfunction is associated with other organ system anomalies, an individual’s life

<table>
<thead>
<tr>
<th>Table 6: 2009 DD FRC Decedent Feeding and Mobility Impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Feeding Method</strong></td>
</tr>
<tr>
<td>G-Tube</td>
</tr>
<tr>
<td>With Assistance</td>
</tr>
<tr>
<td>Independent</td>
</tr>
<tr>
<td>Without support</td>
</tr>
</tbody>
</table>

Table 7: Neuropsychiatric Disorders by Axis

<table>
<thead>
<tr>
<th>Axis I Disorders</th>
<th>Axis II Mental Retardation Level of Severity</th>
<th>Cognitive (N = 22)</th>
<th>Adaptive (N= 22)¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bipolar Disorder with Psychotic features</td>
<td>Profound</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Dementia</td>
<td>Severe</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Depressive Disorder</td>
<td>Moderate</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Impulse Control Disorder, NOS</td>
<td>Mild</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Intermittent Explosive Disorder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td></td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Poly Substance Abuse</td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

¹ Adaptive functioning is a crucial component of the diagnosis for mental retardation. However, only 3 cases reviewed reported current levels of adaptive functioning.
expectancy may be shortened. It is not uncommon that severity of cognitive impairment is correlated to other health risks. As Table 7 depicts, of the 22 cases reviewed during 2009, 15 decedents had a DSM-IV Axis I diagnoses (Endnote #3, see page 12). The Axis I diagnostic disorders represented were: Bi-polar Disorder; Dementia, Schizophrenia, Intermittent Explosive Disorder N.O.S., and Substance Abuse. Although the District records levels of Mental Retardation in terms of both cognitive and adaptive functioning, diagnostic levels are usually made in terms of cognitive functioning. The following degrees of severity reflect the levels of intellectual (cognitive) impairment of the decedents reviewed:

♦ Profound Mental Retardation, 11
♦ Severe, 1
♦ Moderate, 5
♦ Mild, 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 disabilities who received services from the Department on Disability Services. Of the 22 cases reviewed in 2009, 9 decedents were autopsied and 11 decedents had external examinations. Medical examiners reviewed the medical records of the remaining two decedents. Of the 11 decedents that received External Examinations, one died in 2007, and ten died during 2008.

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 medical and investigatory facts concerning the circumstances leading to and surrounding the death, in conjunction with the findings at autopsy and laboratory tests. Twenty of the 22 decedents reviewed in 2009 were determined to be Natural deaths. The remaining 2 deaths were determined to be Accidents.

CAUSE OF DEATH

As Table 8 indicates, of the 22 deaths reviewed during 2009, ten resulted from diseases of the Cardiovascular System, mainly Hypertension and Arteriosclerosis. In four cases, Gastrointestinal Systems disorders were the causes of the death. Cancer and Respiratory disease caused two deaths, while Blunt Injury, Genetic Disorder, Sepsis, and Intoxication were the individual causes of death in four cases.
<table>
<thead>
<tr>
<th>Causes of Death</th>
<th>Number of Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular System</td>
<td>10</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
</tr>
<tr>
<td>Gastrointestinal System</td>
<td>4</td>
</tr>
<tr>
<td>Genetic Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Intoxication</td>
<td>1</td>
</tr>
<tr>
<td>Blunt Injury</td>
<td>1</td>
</tr>
<tr>
<td>Respiratory Disease</td>
<td>2</td>
</tr>
<tr>
<td>Sepsis</td>
<td>1</td>
</tr>
</tbody>
</table>
SECTION III: DD FRC 2009
RECOMMENDATIONS
During calendar year 2009, based on the fatality review of 22 cases, the DD FRC issued 13 recommendations to address the physical, and medical needs of the consumers living with developmental disabilities in the District of Columbia. Recommendations also address improvements necessary to facilitate the training needs of the District’s contractual providers for DDS consumers.

<table>
<thead>
<tr>
<th>FRC Recommendation</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>DDS should ensure that RCM follows through with implementing the recommendations included in the Columbus Report.</td>
<td>DDS Quality Improvement Specialist monitored the provider to ensure the plan of correction was being implemented as it was written. The Issues were closed by DDS on 12/28/10 after the Quality Improvement Specialist determined the provider has implemented their plan of correction as it was written.</td>
</tr>
<tr>
<td>DDS should take immediate steps to bring the five remaining DDA customers who are currently residing in the residential facility in Massachusetts back to facilities in the District and/or metropolitan area.</td>
<td>DDS is working with the individual and their families and their legal representatives to plan for appropriate relocation back to the District as appropriate.</td>
</tr>
<tr>
<td>DDS should issue a medical alert to all MR providers and staff to emphasize the importance of screening, diagnoses and treatment of diabetes for all clients due to their potential for atypical presentations, increased risks due to certain medications and at times their inability to communicate symptoms.</td>
<td>DDS has issued a medical alert to all providers outlining the importance of screening, diagnoses and treatment of diabetes.-DDS Health and Wellness nurses along with DCHRP nurses will continue to assess the individuals being served to ensure they are receiving all proper medical screening and all medical treatment is being provided in a timely manner. DDS issued a medical alert to all DDS providers. DCHRP is currently conducting training and providing technical assistance to the provider community on the signs and symptoms of Diabetes to enhance early detection. By 9/2009 DDS will ensure all providers are trained in signs and symptoms of Diabetes. The Health and Wellness Unit along with DCHRP will monitor the assessments being used by the provider community for Diabetes screening.</td>
</tr>
<tr>
<td>DDS should consider removing the medications section of the Health Passport and instead instruct that the most current MAR be attached to the consumer’s Health Passport to ensure that accurate and up-to-date medications are listed with this document</td>
<td>DDS rejected this recommendation. The MAR’s for the current month are usually locked in the nurses stations. The health standard contains all medications listed on the Health Passport which accompanies the individual to all medical appointments.</td>
</tr>
<tr>
<td>DDS should provide care guidelines for individuals with Down Syndrome to the community providers. This should include health concerns common to these individuals including hypothyroidism, gastro esophageal reflux and esophageal dysmotility</td>
<td>DDS health and wellness division has partnered with DCHRP to provide technical assistance to the provider community. DCHRP along with DDS health and wellness division will prepare guidelines to be disseminated in the provider community about Down Syndrome and its common health concerns.</td>
</tr>
<tr>
<td>FRC Recommendation</td>
<td>Response</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------</td>
</tr>
<tr>
<td>DDS should provide training for group home and other facility staff related to how to handle emergencies including the medical documentation that should be made available at time of transport to the hospital.</td>
<td>DDS provided mandatory training to the provider community which include: emergency protocols as well as the Health Passport (which is the medical documentation that accompanies individuals when they are sent to a hospital). DDS continue to monitor providers that are in need of the mandatory DDS training to verify that all provider staff training is up to date. Quality Management Division BASA team ensures that providers have current Medical passports for all the individuals they serve. The BASA team ensures all the information is current and accurate. DDS BASA team reviews all Medical passport and emergency plans for the agency certification. Quality Management Division Specialist along with Service Coordination ensure that all individuals being served by DDS have a current and accurate Health Passport. As of 1/2009 all individuals being served by DDS have current Health Passports, that include all medical diagnosis, medication, and medical history.</td>
</tr>
<tr>
<td>DDS should ensure that Associated Community Services, Inc. implements the following recommendations include in the Columbus Report: 1. Ensure that the problems identified regarding adequate follow-up of abnormal tests are addressed in a timely manner. 2. Develop an active problem list that is current and comprehensive and is prominently filed in the record so that all health care providers have easy access to this information. 3. Develop a process to ensure that Health Care Plans are dated, signed and contain accurate information about the individual.</td>
<td>DDS Quality Improvement and enhancement team reviews all Medical passports and Health Care Management Plans for the agency certification. Quality Management Division Specialist along with Service Coordination ensures that all individuals being served by DDS have a current and accurate Health Passport and Health Care Management Plan. The plan must be signed and dated by the provider RN, also show oversight by the provider nurse in her monthly nursing notes.</td>
</tr>
<tr>
<td>DDS Should ensure that case managers and IDT’s follow-up to ensure needed services are provided in a timely manner and clearly document any barriers related to not obtaining needed services (i.e. physical therapy, etc.).</td>
<td>DDS service coordinator monitoring tool has a section that outlines all services provided and services needed. Service coordinators monitor each individual monthly to ensure all services needed are provided. During monitoring reviews, the service coordinator will check on services needed but not provided to the individual and put notes in the MCIS system along with steps taken to ensure that individual receives the services they need. If services go a month without being provided an alert is put into the Alert Resolution System to be monitored until resolved. The service coordination monitoring tool was modified in August 2006, to ensure it specifies services to be provided and any unmet needs.</td>
</tr>
<tr>
<td><strong>FRC Recommendation</strong></td>
<td><strong>Response</strong></td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>DDS should ensure:</strong></td>
<td><strong>DDS Health and Wellness unit along with DCHR will offer training</strong></td>
</tr>
<tr>
<td>• Case managers are provided with adequate training on the management of individuals with HIV disease and AIDS with emphasis on the need for regular follow-up by an HIV Specialist and taking measures to ensure the individual is compliant with his medication regime as this has been shown to improve the prognosis for persons with HIV infection.</td>
<td><strong>to all DDS Service Coordinator’s and providers serving individuals living with HIV or AIDS. This training will be included in the mandatory Phase II training.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>DDS Health and Wellness Director along with DCHR will offer trainings to all DDS Service Coordinators on HIV and AIDS. The training should be offered by 10/1/10.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>DDS Health and Wellness Director will meet with DCHR nurses to gathered information about presenting training on HIV and AIDS to DDS Service Coordinator’s DCHR will be putting together a training manual which will be used in the training.</strong></td>
</tr>
<tr>
<td>• Case managers understand HIV disease is life changing for the individual and their family. Spiritual and emotional support is often needed as the person’s condition progresses. Encourage staff to regularly visit the individual and work with the family to ensure needed supports (e.g., day services, counseling, nursing, etc.) are provided.</td>
<td><strong>DDS should discuss the following recommendations with the staff of the St. Thomas More Nursing and Rehab Center:</strong></td>
</tr>
<tr>
<td></td>
<td><strong>There is an accurate and current active problem list that is a separate document this is easily accessible by all health care providers.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>All individuals served by DDS have a Health Care Management Care Plan and DDS requires that the plans are regularly updated based on changing needs and that the Plan should be followed by all health care providers serving individuals.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>DDS does not have authority over nursing facilities.</strong></td>
</tr>
<tr>
<td>• Case managers ensure all appropriate clinicians are actively involved in annual planning so ISP action plans comprehensively address the individual’s medical and physical needs. When appropriate, individuals with significant medical issues should have a plan to address non-compliance with medical treatments/services.</td>
<td><strong>There are clearly documented periodic reviews (e.g., annual, quarterly) completed by the PCP of the individual overall status related to the management of active problems</strong></td>
</tr>
<tr>
<td></td>
<td><strong>There is active participation by the interdisciplinary team (beyond the annual planning process to assure a holistic approach overall management of care provided and there is full participation of the interdisciplinary team at the annual reviews.</strong></td>
</tr>
</tbody>
</table>
DDS should ensure that the provider addresses the following recommendations highlighted in the Columbus Report:

1. DC Health Care, Inc.’s PCP should provide plans to address the following:

   Need for documentation of rationales, especially for choosing a new gastroenterologist in 11/07 and for new medications in the regimen after a hospitalization; Need to provide adequate information (past medical history, results of diagnostic tests) to consultants; Need to document the basis for medical decisions; How to address timeliness of care and lack of follow-up of recommendations; Diagnosis and treatment of H. pylori; Use of rectal suppositories for constipation; Chronic iron therapy; Diet recommendations for gastroparesis; Accuracy of physical examination findings on annual medical evaluations; and Need to document medications indications in the physician orders.

2. DC Health Care, Inc. should provide plans to address the following:

   Need to provide quality information in quarterly pharmacy reviews; Need to provide quality information on the Health Passport; Need for the signature of staff who document on consultation forms; and Need for more in-depth discussion of health information in the ISP.

3. DC Health Care, Inc. should ensure nursing staff complete one comprehensive Health Care Management Plan that is maintained current for each individual supported and that nursing progress notes are documented at a frequency commensurate with the individual’s health issues and whenever a change in condition occurs.

DDS has forwarded a copy of the Columbus recommendations to DC Heath Care Inc., via email. A hard copy was also mailed to the provider’s corporate office.

DDS has forwarded the Columbus recommendations to DC Health Care Inc., via email. A hard copy was also mailed to their corporate office. DC Health Care Inc., was given two weeks to respond to recommendations from the date received and requested to describe in detail action steps to satisfy the recommendations. **Update 12/10/09:** Columbus recommendations were mailed out on June 10, 2009. DC Health Care Inc., sent their response on June 25, 2009. The Quality Improvement Specialist assigned to DC Health Care Inc., has completed monitoring of DC Health Care Inc., September 2009. As of 10/2009 these recommendations are closed.

DC Health Care Inc., is still working on answering the recommendations from Columbus. DDS Quality Management Division Specialist is working with DC Health Care Inc., to ensure they are responding to the recommendations and implementing their written plan of correction. **Update 12/10/09:** The Quality Improvement Specialist assigned to DC Health Care Inc., has completed monitoring of DC Health Care Inc., on September 2009. As of 10/2009 these recommendations are closed.

DC Health Care Inc., will provide better health care monitoring, oversight and timeliness of scheduled appointments for individuals being served.

Quality Management Division Specialist assigned to DC Health Care Inc., will monitor this provider on an on-going basis to ensure the provider remains in compliance with their plan of corrections and report progress monthly MCIS notes, as well as at monthly staff meetings.
DDS should ensure that post hospitalization clients are monitored closely and activities immediately following are limited and appropriate.

DDS should ensure that all providers ensure:

- All laboratory tests ordered include documentation that the PCP has reviewed the results and commented on abnormal values.
- There is consistent follow-up by the PCP of consultant recommendations.

DDS Service Coordinators monitor individuals daily with at least 2 face to face visits within the first week upon release from the hospital. Service Coordinators will keep abreast of individuals health conditions through communication with the provider nurse and direct care staff.

DDS Service Coordinators participate in the discharge meeting at the hospital. DDS Service Coordinators will collaborate with the DDS Health and Wellness nurse assigned to the provider to ensure best health practices are implemented. DDS Health and Wellness nurses assigned to the provider will also monitor the health status of the individuals and offer guidance to the provider nurse. DDS Health and Wellness nurse along with the DDS Service Coordinator will encourage the provider nurse to develop a communication book with the PCP to ensure the PCP is informed of any health change with the individual. The communication book also serves as a record that the PCP and the provider nurse are having dialog about the individual and their health needs.

DDS Service Coordinators and the DDS Health and Wellness nurses review the communication book during the monthly monitoring to ensure communication between the nurse and PCP and that medical follow up is being scheduled.

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DDS Service Coordinators participate in the discharge meeting at the hospital. DDS Service Coordinators will collaborate with the DDS Health and Wellness nurse assigned to the provider to ensure best health practices are implemented. DDS Health and Wellness nurses assigned to the provider will also monitor the health status of the individuals and offer guidance to the provider nurse. DDS Health and Wellness nurse along with the DDS Service Coordinator will encourage the provider nurse to develop a communication book with the PCP to ensure the PCP is informed of any health change with the individual. The communication book also serves as a record that the PCP and the provider nurse are having dialog about the individual and their health needs.

DDS Service Coordinators and the DDS Health and Wellness nurses review the communication book during the monthly monitoring to ensure communication between the nurse and PCP and that medical follow up is being scheduled.

DDS has forwarded the Columbus recommendations to Comprehensive Care II Inc., via email on September 30, 2009. Comprehensive Care II Inc., was given two weeks to respond to recommendations from the date received and to describe in detail action steps to satisfy recommendation. Comprehensive Care II Inc., sent their response on October 27, 2009. The Quality Improvement Specialist assigned to Comprehensive Care Inc., has completed monitoring of Comprehensive Care II Inc., November 4, 2009. As of 11/2009 these recommendations are closed.

Quality Management Division Specialist assigned to Comprehensive Care II Inc., will monitor this provider on an ongoing basis to ensure the provider remains in compliance with their plan of correction.
| Endnote # 1 | 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 Developmental 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.
III. DUTIES

The duties of the Committee shall include:

A. Expediously 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 PROCEDURE

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

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.

[Signature]

**ADRIAN M. FENTY**

**MAYOR**

ATTEST: [Signature]

**STEPHANIE D. SCOTT**

**SECRETARY OF THE DISTRICT OF COLUMBIA**
## Glossary of Terms

<table>
<thead>
<tr>
<th>Terms</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autopsy Report</td>
<td>A detailed report consisting of the autopsy procedure, microscopic and laboratory findings, a list of diagnoses, and a summary of the case.</td>
</tr>
<tr>
<td>CRF/MR</td>
<td>Community Residential Facility for individuals diagnosed with an intellectual disability (MR)</td>
</tr>
<tr>
<td>Group Home</td>
<td>Licensed homes for persons with mental retardation that range in size from four (4) to eight (8) customers</td>
</tr>
<tr>
<td>Hospice</td>
<td>A program or facility that provides special care for people who are near the end of life and for their families</td>
</tr>
<tr>
<td>ICF/MR</td>
<td>A licensed residential facility certified and funded through Title XIX (Medicaid) for consumers diagnosed with an intellectual disability (MR)</td>
</tr>
<tr>
<td>Level of Disability</td>
<td>Cognitive and adaptive impairment ranging from mild to profound</td>
</tr>
<tr>
<td>Life Expectancy</td>
<td>The average expected length of life; the number of years somebody is expected to live</td>
</tr>
<tr>
<td>Medicaid Waiver</td>
<td>Provides rehabilitative, behavioral and medical supports to individuals with intellectual and developmental disabilities in residential community, and private home settings</td>
</tr>
<tr>
<td>Natural Home</td>
<td>Consumers residing in the home of a parent, family members or independently</td>
</tr>
<tr>
<td>Neurological Conditions</td>
<td>Disorders of the neuromuscular system (the central, peripheral, and autonomic nervous systems, the neuromuscular junction, and muscles)</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>A long-term healthcare facility that provides full-time care and medical treatment for people who are unable to take care of themselves</td>
</tr>
<tr>
<td>Skilled Care</td>
<td>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</td>
</tr>
<tr>
<td>Specialized Home Care</td>
<td>A private home living environment for three (3) or less individuals (also includes foster care)</td>
</tr>
<tr>
<td>Supervised Apartments</td>
<td>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</td>
</tr>
<tr>
<td>Ward</td>
<td>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</td>
</tr>
</tbody>
</table>
### Deaths Reviewed that Occurred in 2007:

<table>
<thead>
<tr>
<th>Age/Race Sex</th>
<th>Cause of Death</th>
<th>Manner of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>60/Blk/Female</td>
<td>Pulmonary Embolus due to Dehydration following Blunt Impact Head Trauma with Subarachnoid Hemorrhage</td>
<td>Accident</td>
</tr>
<tr>
<td>62/Wht/Female</td>
<td>Complications of Volvulus of Sigmoid Colon, Operated</td>
<td>Natural</td>
</tr>
</tbody>
</table>

### Deaths Reviewed that Occurred in 2008:

<table>
<thead>
<tr>
<th>Age/Race Sex</th>
<th>Cause of Death</th>
<th>Manner of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>24/Blk/Male</td>
<td>Pulmonary Thromboembolism due to Deep Venous Thrombosis due to Decreased mobility</td>
<td>Natural</td>
</tr>
<tr>
<td>58/White/Female</td>
<td>Ateriosclerotic Cardiovascular Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>24/Blk/Male</td>
<td>Seizure Disorder due to Cerebral Palsy</td>
<td>Natural</td>
</tr>
<tr>
<td>84/Blk/Female</td>
<td>Cardiopulmonary Arrest due to Myocardial Infarction due to Diabetes Mellitus due to Hypertension</td>
<td>Natural</td>
</tr>
<tr>
<td>94/Wht/Male</td>
<td>Hypertensive and Ateriosclerotic Cardiovascular Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>75/Blk/Female</td>
<td>Hypertensive and Ateriosclerotic Cardiovascular Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>21/Blk/Female</td>
<td>Complications of Congenital Neurologic Disorder</td>
<td>Natural</td>
</tr>
<tr>
<td>69/Wht/Male</td>
<td>Complications of Small Intestinal Obstruction</td>
<td>Natural</td>
</tr>
<tr>
<td>78/Blk/Male</td>
<td>Complications of Hypertensive and Ateriosclerotic Cardiovascular Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>57/Wht/Female</td>
<td>Down’s Syndrome with Congenital Heart Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>57/Blk/Male</td>
<td>Diffuse, High Grade Non-Hodgkin’s Lymphoma</td>
<td>Natural</td>
</tr>
<tr>
<td>63/Blk/Female</td>
<td>Hypertensive and Ateriosclerotic Cardiovascular Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>32/Blk/Male</td>
<td>Chronic Pulmonary Disease</td>
<td>Natural</td>
</tr>
<tr>
<td>81/Blk/Male</td>
<td>Complications Following Exploratory Laparotomy for Diagnosis of Upper Gastrointestinal Hemorrhage unknown etiology</td>
<td>Natural</td>
</tr>
<tr>
<td>37/Blk/Male</td>
<td>Aspiration Pneumonia Due to Partial Small Bowel Obstruction Due to Peritoneal Adhesions with Fibrous Band Due to Intra Abdominal Surgery, Remote</td>
<td>Natural</td>
</tr>
<tr>
<td>82/Blk/Female</td>
<td>Colon Cancer</td>
<td>Natural</td>
</tr>
<tr>
<td>27/Blk/Male</td>
<td>Acute Phencyclidine Intoxication</td>
<td>Accident</td>
</tr>
<tr>
<td>39/His/Male</td>
<td>Aspiration Pneumonia</td>
<td>Natural</td>
</tr>
</tbody>
</table>
### Causes of Death - 2009 DD FRC Deaths Reviewed

**Deaths Reviewed that occurred in 2008 Cont’d.**

<table>
<thead>
<tr>
<th>Age/Race Sex</th>
<th>Cause of Death</th>
<th>Manner of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>36/Blk/Female</td>
<td>Pulmonary Thromboembolism due to Deep Leg Vein Thrombosis</td>
<td>Natural</td>
</tr>
<tr>
<td></td>
<td>Urosepsis Pneumonia due to Cerebral Palsy, due to Encephalopathy, due to Obstetric Complications</td>
<td>Natural</td>
</tr>
<tr>
<td>57/Blk/Female</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENT

We wish to acknowledge the dedication and unwaivering 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. It is an act of courage to acknowledge that the deaths of individuals diagnosed with Intellectual and Developmental disabilities is a community problem. 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.