# Table of Contents

Letter to the Mayor .................................................. i

Executive Summary .................................................. 1

Introduction ............................................................. 2

Barriers to the MRDD FRC Process ................................. 3

Mortality Trends .......................................................... 3

  Age ................................................................. 5
  Gender ............................................................. 5
  Race ............................................................... 5
  Ward Data .......................................................... 6
  Location of Death .................................................. 7

Abuse and Neglect Issues ............................................. 8

Cause and Manner of Death .......................................... 8

2004 FRC Recommendations ......................................... 11

Appendices

Appendix A: Mayor’s Order 2001-27
Appendix B: LEXSTAT DC CODE 7-1301.03
Appendix C: Cause of Death of Cases Reviewed in 2004
April 2005

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

On behalf of the Mental Retardation and Developmental Disabilities (MRDD) Fatality Review Committee, I am pleased to present the 2004 Annual Report. During calendar year 2004, 36 persons with MRDD who were served by the Mental Retardation and Developmental Disabilities Administration died. Information in this report is specific to 26 cases that were reviewed by the Fatality Review Committee during the calendar year.

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

As we strive to improve the overall quality of care that persons with mental retardation and developmental disabilities receive in the District of Columbia, we also encourage the citizens to join us in our effort to make the District of Columbia the model for providing this service to the rest of the nation.

Sincerely,

[Signatures]

Dale E. Brown
Chief Medical Examiner/MRDD FRC Co-Chair
Office of the Chief Medical Examiner

Marie-Lydie Y. Pierre-Louis, MD
Chief Medical Examiner/MRDD FRC Co-Chair
Office of the Chief Medical Examiner

Dale E. Brown
Administrator, MRDDA
MRDD FRC Co-Chair
Executive Summary

This is a report of the District of Columbia Mental Retardation and Developmental Disability Fatality Review Committee for 2004. The Mental Retardation and Developmental Disability Fatality Review Committee was established in February 2001, by Mayor’s Order 2001-27, (herein after referred to as the Order). The Order mandates that the Committee, referred to as the Fatality Review Committee, examine events that surround the deaths of District wards or residents 18 years of age and older with mental retardation and/or developmental disabilities.

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

During calendar year 2004, 36 persons with MRDD who were served by MRDDA died. The FRC reviewed 26 cases during the same calendar year. These reviews represent deaths that occurred during calendar years 2001 through 2004. Throughout the fatality review process, the FRC examines an independent investigative report of each individual’s death and a forensic autopsy report. The reports highlight each deceased individual’s social history including family and care giver relationships and living conditions prior to death; medical diagnosis and medical history; services provided; and cause and manner of death. These fatality reviews may lead to identification of systemic health care and service concerns. The Fatality Review Committee recommends strategies to promote comprehensive health care and improve the quality of life for persons with mental retardation and developmental disabilities.

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

Summary of Findings for deaths reviewed in 2004

- 92% of the cases were autopsied
- 88.5% of these deaths reviewed were due to natural causes
- 59% of the Fatality Review Committee’s recommendations have been implemented to date
Introduction

This report is a summary of the work performed by the District of Columbia Mental Retardation and Developmental Disability (MRDD) Fatality Review Committee (hereinafter referred to as the Fatality Review Committee (FRC)). Information in this report is specific to decedents with MRDD who received services from MRDDA and were reviewed during the 12-month period between January 1, 2004 and December 31, 2004. The FRC was established in February 2001, under the authority of Mayor’s Order 2001-27. The Order mandates that the FRC examine events that surround the deaths of District wards or residents 18 years of age and older with mental retardation and/or developmental disabilities.

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

The scope of the fatality review includes the examination of relevant policies and statutes, independent investigative reports and reports of forensic autopsies conducted by the Office of the Chief Medical Examiner. This information highlights each deceased individual’s social history including family and care giver relationships as well as living conditions prior to death; medical diagnosis and medical history; services provided; and cause and manner of death. These reviews examine compliance with regulations and recommendations by service providers, and may lead to the identification of systemic health care and service concerns. The FRC recommends systemic strategies to improve the quality of life for persons with MRDD under the care of the District’s Mental Retardation and Developmental Disabilities Administration (hereinafter referred to as (MRDDA).

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

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

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Barriers to the MRDD FRC Process

Since the establishment of the District of Columbia MRDD FRC in 2001, the FRC has had the opportunity to evaluate some of the existing operational deficiencies and barriers. These barriers have hindered the FRC’s ability to operate effectively, efficiently and in the manner intended. Some of the systemic obstacles that have been identified by the FRC include, but are not limited to, the inability to obtain the information and data required for the reviews timely, the absence of established procedures and the resources to ensure the consideration and implementation of the recommendations. These problems have affected the FRC’s ability to complete reviews within the timeframes designated, determine appropriateness of the services provided and make appropriate recommendations for service, policies and legislative improvements. The FRC members realize that many of the problems that have surfaced are the result of an inability to anticipate the challenges associated with diversity of the distinct operating structures, laws, policies and practices of the various disciplines and agencies, which may conflict with the purpose and goal of the unit.

In an effort to begin to address these issues, the FRC has made recommendations to improve the timeliness for obtaining the information and data required for reviews, and improve the District’s overall review process and collaborative method of operating. Further, the FRC began to conduct a more thorough evaluation of the review process and operational modalities currently in place and developed, and is reviewing these procedures. It is our hope that this evaluation will assist in not only identifying systemic issues and concerns that are obstructive to the process, but that it will also assist in devising ways to streamline information to make the FRC operate more efficiently.

Mortality Trends

During calendar year 2004, 36 persons with MRDD who were served by MRDDA died. While this report will provide demographic data related to the characteristics of the 2004 decedents, the majority of the report focuses on the FRC fatality review activities that occurred during this calendar year. During 2004, 26 fatalities were reviewed. These reviews represent deaths that occurred during calendar years 2001 through 2004.

As shown in Table 1 below, the total number of persons with MRDD served by MRDDA in the District of Columbia for calendar years 2001 through 2004 was 1547, 1703, 1790 and 1915 respectively. The number of deaths per year of MRDD consumers during this period fluctuated from 26 to 36.

Since 2001, the number of deaths reviewed by the FRC has increased yearly, from 9 in 2001 to 26 in 2004, representing an overall increase of 189 percent. Despite the continuous increase in the number of cases reviewed, there continues to be a backlog of cases pending FRC review.
**Table 1: District of Columbia MRDDA Population and Deaths 2001 to 2004.**

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>Number of Deaths</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<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%</td>
</tr>
</tbody>
</table>

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

**Table 1.1: Race of MRDD Population and Fatalities by Year**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>1163</td>
<td>24</td>
<td>1411</td>
<td>17</td>
<td>1467</td>
<td>23</td>
<td>1586</td>
<td>28</td>
</tr>
<tr>
<td>Caucasian</td>
<td>224</td>
<td>8</td>
<td>218</td>
<td>9</td>
<td>200</td>
<td>8</td>
<td>198</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>*160</td>
<td>0</td>
<td>64</td>
<td>0</td>
<td>123</td>
<td>0</td>
<td>131</td>
<td>2</td>
</tr>
</tbody>
</table>

*In 2002, MRDDA implemented the MCIS 3.0. The previous versions of the system did not require the race, however, the new system required that race be documented. During the conversion of the system MRDDA was able to correctly identify the race for the 1,703 consumers on record at the end of 2002, and the number of consumers with the race marked as other in 2001 was significantly reduced.

**Summary of Case Review Findings**

The information contained in this section will cover the data and findings that resulted from cases reviewed over a four-year period, with a specific emphasis on those reviewed during calendar year 2004. The tables and graphs provide information related to those cases reviewed during 2004 (n=26). Data in these tables also clearly specifies the year of the death despite the fact that the review occurred during 2004.

At the close of 2004, there were 43 cases in which reviews remained pending. These cases spanned years from 2002 through 2004. Table 2 depicts the number of cases reviewed and the number of cases pending review for each of these years.

**Table 2: FRC Cases Pending Review**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Deaths By Year</th>
<th>Number of Cases Reviewed By Year</th>
<th>Number of Cases Pending Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>36</td>
<td>13</td>
<td>23</td>
</tr>
<tr>
<td>2003</td>
<td>31</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>2002</td>
<td>26</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>2001</td>
<td>32</td>
<td>32</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>125</td>
<td>80</td>
<td>45</td>
</tr>
</tbody>
</table>

*FRC review of these cases is pending completion of the Columbus Investigation reports.*
Age and Mortality

In calendar year 2004, the FRC reviewed the deaths of 26 persons with MRDD who ranged in age from 23 to 87 years. Of the 26 deaths reviewed, 8 (31%) were 61 years of age and older, 9 (35%) were between 51-60 years, 4 (15%) were age 41-50, 1 (4%) were 31-40, and 4 (15%) were age 21-30.

Table 3: Decedents by Age Range and Gender

<table>
<thead>
<tr>
<th>Age Range</th>
<th>2001 N=4</th>
<th>2002 N=2</th>
<th>2003 N=7</th>
<th>2004 N=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>18-20</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>21-30</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>31-40</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>41-50</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>51-60</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>61-over</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3 illustrates the number of decedents by age range and gender for each calendar year reviewed.

Race and Mortality

Table 4: Race of the Decedents Reviewed by Calendar Year.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Caucasian</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

As shown in Table 4, of the 26 cases reviewed in 2004, 20 (77%) were Black and, 5 (20%) were Caucasian.
Ward Data

Ward of residence refers to the decedent’s residential address at the time of death. Addresses included natural homes, foster care, intermediate care facilities for persons with mental retardation, supervised apartments and nursing homes. During calendar year 2004, out of the 26 fatalities reviewed, the majority of the decedents were residing in the District at the time of their deaths \( (n = 19, \text{ or } 73\%) \). Seven decedents \( (27\%) \) were residents of other states, five resided in Maryland, and two resided in Virginia.

Table 5: Ward/Jurisdiction of Residence At the Time of Death

<table>
<thead>
<tr>
<th>District Ward/Jurisdiction</th>
<th>Total Deaths Reviewed in 2004</th>
<th>Deaths By Calendar Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2001</td>
<td>2002</td>
</tr>
<tr>
<td>One</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Two</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Four</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Seven</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Eight</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Maryland</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Virginia</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Because of the backlog of fatality cases that are pending investigations from calendar years 2001 through 2003, it is difficult to evaluate mortality trends. However, the following observations were highlighted during the 2004 MRDD FRC case review meetings:

Decedents Residing in Out-of-State Facilities

- The decedents who resided outside the District were in the care of MRDDA and had been placed in numerous types of out-of-state facilities that included three nursing homes, two natural homes, one supervised apartment, and one group home.
- These decedents ages ranged from 23 to 76, with the majority being over the age of 50 \( (n = 5, \text{ or } 71\%) \).
- Consistent with the overall population, the majority of the Maryland and Virginia decedents were Black \( (n = 5, \text{ or } 71\%) \).
Decedents Residing in the District of Columbia

- Out of the 19 decedents who were residing in the District at the time of their deaths, the majority resided in Wards One, Seven and Eight (n = 12, 63%) and most of these decedents resided in Ward Seven (n = 5).
- Three of the 19 District decedents died during 2001. Two thirds (n = 2) were residents of Ward One and one was a resident of Ward Seven. All the decedents were Black and under the age of 50 years. Two were females and one male. The Ward One residents were living in a nursing home and natural home; the Ward Seven resident resided in a group home facility.
- The two 2002 decedents resided in Wards Three and Seven and both resided in group home facilities. One of the decedents was White and one was Black, both were over the age of 50 years. One was female and one was male.
- Four of the seven deaths reviewed from 2003 calendar year resided in the District. Their ages ranged from 23 to 76 years; all were females; and three were Black and one was White. The types of facilities included a natural home in Ward Two, a group home in Ward Five, and nursing homes in Ward Six and Ward Eight.
- Ten of the 19 District MRDD fatalities occurred during 2004. The races of the decedents included eight Black, one White and one Asian. The ages ranged from 45 to 79, with the majority being over 50 years of age (n = 8). There were equal numbers of female and male decedents (n = 5 each). The facilities included four intermediate care facilities (two in Wards Seven and Eight each); two apartments in Wards Four and Seven; two group homes in Wards One and Four; one natural home in Ward Eight; and one nursing home in Ward Three.

Location at time of Death

Of the cases reviewed, deaths occurred in locations that included hospitals, nursing homes, and group homes. Table 6 presents the number of individuals who died by location during calendar years 2001 through 2004.

Table 6: Location at time of Death

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>2001 N=4</th>
<th>2002 N=2</th>
<th>2003 N=7</th>
<th>2004 N=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Hospice</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Residential</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 6 illustrates that of the 26 cases reviewed in 2004, 22 (85%) died in a hospital setting and 3 (12%) died in a nursing home.
Abuse and Neglect

Abuse and neglect is defined as wrongful treatment of a customer that endangers his or her physical or emotional well-being, through the action or inaction of anyone, including, but not limited to, another customer, an employee, intern, volunteer, consultant, contractor, visitor, family member, guardian or stranger, whether or not the affected customer is, or appears to be, injured or harmed.2

Of the 26 cases reviewed in 2004, there was one (1) allegation of abuse that occurred within 6 months of death as reported by Incident Management Investigations Unit (hereinafter referred to as IMIU). The investigative report indicated that this case was not substantiated and the necessary corrective action, e.g., staff training on effective communication with non-verbal consumers, was taken. In one case, the circumstances leading to the death remain unclear.

Cause and Manner of Death

Pursuant to Mayor's Order 2004-76, "Autopsies of Deceased Clients of the Mental Retardation and Developmental Disability Administration",3 autopsies must be performed on all persons with MRDD who die in the District of Columbia and received services and support from MRDDA. Of the 26 cases reviewed, 24 were autopsied; 1 was an external examination; and 1 was declined.4

The District’s Office of the Chief Medical Examiner (OCME) accepted jurisdiction and performed autopsies on 18 (69%) of the 26 decedents whose cases were reviewed. Six (23%) of the autopsies were performed in out-of-state facilities, in one case (4%) an external examination was performed and in one case (4%) jurisdiction was declined. The autopsy rate for the District’s MRDD cases reviewed in 2004 was 92%.

Table 7 presents information on the wide variety of neurologic conditions affecting the MRDD population including genetic defects, developmental malformations or diseases and their complications. In many cases more than one condition was present in the same individual.

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4 The previous Mayor's Order mandating autopsies of deceased clients of MRDDA expired before reestablishment of the mandate in Mayor's Order 2004-76. It was during the lapse period that the external examination was performed and, in one case, jurisdiction was declined pursuant to D.C. Official Code § 5-1401 et seq. (2001).
Table 7: Neurologic Conditions

<table>
<thead>
<tr>
<th>Neurologic Disorder</th>
<th>Consumers Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Retardation, not otherwise specified</td>
<td>15</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>4</td>
</tr>
<tr>
<td>Down’s Syndrome</td>
<td>4</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>2</td>
</tr>
<tr>
<td>Seizure</td>
<td>4</td>
</tr>
<tr>
<td>Cri du Chat Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>2</td>
</tr>
<tr>
<td>Complications of Leptomeningitis</td>
<td>1</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>3</td>
</tr>
<tr>
<td>Autism</td>
<td>1</td>
</tr>
<tr>
<td>Hydranencephaly (Perinatal Event)</td>
<td>1</td>
</tr>
<tr>
<td>Post Traumatic Developmental Disability</td>
<td>1</td>
</tr>
</tbody>
</table>

Cause of Death

Cause of death is defined as the underlying pathological condition or injury that initiates the chain of events which brings about the demise. The majority of the deaths in the MRDD cases reviewed in 2004 were due to medical conditions as listed in Table 8 below.

Table 8: Cause of Death

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Number of Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologic Diseases</td>
<td>6</td>
</tr>
<tr>
<td>Cardiovascular Diseases (Hypertension, Atherosclerosis)</td>
<td>10</td>
</tr>
<tr>
<td>Cancer</td>
<td>3</td>
</tr>
<tr>
<td>Gastrointestinal Diseases</td>
<td>2</td>
</tr>
<tr>
<td>Trauma</td>
<td>2</td>
</tr>
<tr>
<td>Drug Intoxication</td>
<td>1</td>
</tr>
<tr>
<td>Therapeutic Complications</td>
<td>2</td>
</tr>
</tbody>
</table>

The results in Table 8 indicate that the Neurologic disorders that placed these individuals in this special category were the underlying cause of death in 6 cases. In the remaining population, cardiovascular diseases were the most prevalent causes of death, 10 cases, followed by cancer, 3 cases. Therapy related measures were associated with 2 deaths.

Pneumonia/Bronchopneumonia was the terminal cause of death in 7 cases, complicating both Neurologic and Cardiovascular diseases.
Manner of Death

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

The results in Table 9 indicate that of the 26 deaths reviewed during 2004, the manner of death at autopsy was determined to be natural for 23 (88.5%) of the decedents, accidental for 2 (7.5%) of the deaths, and undetermined for 1 (4%) of the deaths.

<table>
<thead>
<tr>
<th>Manner of Death</th>
<th>Number of Deaths</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural</td>
<td>23</td>
<td>88.5%</td>
</tr>
<tr>
<td>Accident</td>
<td>2</td>
<td>7.5%</td>
</tr>
<tr>
<td>Suicide</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Homicide</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Undetermined</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>100%</td>
</tr>
</tbody>
</table>
2004 Recommendations

During calendar year 2004, the FRC reviewed 26 cases and made eight recommendations in the areas of health and safety. Additionally, a number of other concerns related to previously adopted recommendations in the areas of end of life issues, documentation and training continued to be highlighted. The 2004 adopted FRC recommendations are as follows:

1. MRDDA provide training on coordinated services and support for senior (elderly) MRDDA consumers.
2. OCME investigators should be made aware of medications and other co-existing disorders by DHS/IMIU via the DHS/MRDDA Fatality Review Form.
3. MRDDA continue plans for training regarding risk factors and to use the Board of Nursing as experts and support on MRDDA’s efforts.
4. All health care issues are incorporated in the ISP in a coordinated plan of care.
5. MRDDA follow up with the Providers Medical Passport System Review Form.
6. DHS/IMIU investigation report (via Columbus)\(^5\) includes a review of day programs that offer medical support during the day. MRDDA shall provide a list of all Medical Day providers to IMIU.
7. MRDDA send a letter to VOCA regarding the practices of this physician with a carbon copy to the Medical Board and OIG.
8. MRDDA send a reminder to the provider community regarding MRDDA’s Medical Care Protocols.

Conclusion

By reviewing the information from each death, the FRC hopes to initiate necessary changes within each level to institute safer services for all individuals being served by MRDDA. An important outgrowth of this process is the recognition of best practices, and recommendations to implement those practices as systemic changes. The FRC understands that the information submitted for review cannot change the circumstances that led to that individual’s death, however, this body strives to use the information submitted for review in each case to identify trends, direct training needs, recommend development and/or modification of provider policies, or to modify city policies to address systemic issues to improve care. Toward this end, new FRC procedures have been drafted to review and ensure the implementation of adopted recommendations.

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\(^5\) The Columbus organization is a contractor with the District of Columbia Department of Human Services. This organization conducts mortality investigations for deceased persons with mental retardation and developmental disabilities.
Appendices

Appendix A: Mayor’s Order 2001-27
Appendix B: LEXSTAT DC CODE 7-1301.03
Appendix C: Cause of Death of Cases Reviewed in 2004
GOVERNMENT OF THE DISTRICT OF COLUMBIA

ADMINISTRATIVE ISSUANCE SYSTEM

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

ORIGINATING AGENCY: Office of the Mayor

By virtue of the authority vested in me as Mayor of the District of Columbia, pursuant to section 422(2) of the District of Columbia Home Rule Act of 1973, as amended, 87 Stat. 790, Pub. L. No. 93-198, D.C. Code § 1-242(2) (1999 Repl.), it is hereby ORDERED as follows:

I. ESTABLISHMENT

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

II. PURPOSE

The District of Columbia MRDDA Fatality Review Committee shall examine events and circumstances surrounding the deaths of District Wards (DWs) with mental retardation or developmental disability in order to: gather and analyze empirical evidence about fatalities in this population; safeguard and improve the health, safety and welfare of these DWs; reduce the number of preventable deaths; and promote improvement and integration of both the public and private systems serving these vulnerable District residents.

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

III. DUTIES

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

B. Identify the causes and circumstances contributing to deaths of DWs;
C. Review and evaluate services provided by public and private systems which are responsible for protecting or providing services to DWs, and 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 aggregate), identify strengths and weaknesses in the governmental and private agencies and/or programs that serve these DWs, and hence make recommendations to the Mayor (and/or to these entities directly) to implement systemic changes to improve services or to rectify deficiencies. Such recommendations may address, but are not limited to, proposing statutes, policies or procedures (both new or amendments to existing ones); modifying training for those persons who provide services related to these DWs; enhancing coordination and communication among entities providing or monitoring services for DWs; and facilitating investigations of fatalities.

IV. FUNCTIONS

The Committee shall:

A. Within ninety (90) days of the date of the Mayor's Order establishing this committee, develop and issue procedures governing its overall operation. The procedures shall include, at a minimum, the following:

1. Methods by which deaths of District of Columbia wards (DWs) are identified and reported to ensure expeditious and excellent reviews;
2. A process by which fatality cases are screened and selected for review;
3. Methods for assembling a properly composed committee and conducting the reviews;
4. A method for ensuring that all information identifying DWs, their families and others associated with the case or the circumstances surrounding the death, including witnesses and complainants, is protected against disclosure. This is to ensure that steps are taken to protect an individual's right to privacy both in the conduct of the investigations, dissemination of information to Committee members, reporting as required by the Mayor's Order and maintenance of case records for the Committee;
5. A systematic method for gathering individual and cumulative data from the reviews;
6. A method for ensuring that information required for the reviews is made available timely for use by the Committee;
7. A method for reviewing whether recommendations generated by the Committee have been implemented and identifying problems related to obstacles/barriers to implementation; and
8. A method for evaluating the work of the Committee which also considers community responses to the deaths of DWs.
B. Promulgate recommendations based on the findings of the reviews that support the development and implementation of new or improved services, practices, policies or procedures of the agencies and programs (public or private) that serve these DWs, and that will enhance the protection of the target population; and

C. By 30 April of each year, produce an annual report that provides information and statistical data obtained from the reviews of deaths that occurred during the previous calendar year. The annual report shall be submitted to the Mayor and made available to the public. The information to be contained in the report shall include, at a minimum:

1. Statistical data on all fatalities of DWs reviewed by the Committee, including numbers reviewed, demographic characteristics of the subjects, and causes and manners of death;
2. Analyses of the data generated by the reviews, to demonstrate the types of cases reviewed (which may include illustrative case vignettes without identifiers), similarities or patterns of factors causing or contributing to the deaths, and trends (both temporal and geographic); and
3. Recommendations which are generated from the reviews, including service enhancements, systemic improvements or reforms, and changes in laws, policies, procedures or practices that would better protect DWs, and could prevent future deaths.

V. COMPOSITION OF THE FATALITY REVIEW COMMITTEE

Members shall be appointed by the Mayor based on individual expertise in relevant disciplines and their familiarity with the laws, standards and services related to the protection of the health and welfare of these DWs. The Committee membership shall comprise:

A. Eight (8) public members from the community who are not employees of the Government of the District of Columbia. All efforts shall be made to ensure proportionate representation from each ward of the District;
B. Two (2) faculty members from Schools of Social Work from colleges/universities in the District of Columbia;
C. Two (2) physicians who practice in the District of Columbia with experience in the evaluation and treatment of persons with mental retardation or developmental disabilities;
D. Ex officio members shall include the directors or their designees from the following District government departments or agencies, or their successor programs:
1. Department of Human Services (DHS):
   a. Mental Retardation and Developmental Disabilities Administration (MRDDA)
   b. Office of Inspections and Compliance (OIC)
   c. Rehabilitation Services Administration (RSA)
   d. Adult Protective Services (APS)
2. Office of the Chief Medical Examiner (OCME)
3. Department of Health (DOH)
   a. Health Regulation Administration (HRA)
   b. Medical Assistance Administration (MAA)
   c. State Center for Health Statistics (SCHS)
   d. Bureau of Injury and Disability Prevention (BIDP)
4. Metropolitan Police Department (MPD), Criminal Investigations Division
5. Office of the Corporation Counsel (OCC)
7. Commission on Mental Health Services (CMHS)
8. Fire Department and Emergency Medical Service, EMS Director

E. The following agencies may be included, should they agree to participate:
   1. Office of the United States Attorney for the District of Columbia
   2. Superior Court of the District of Columbia

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

VI. TERMS

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

A. A member appointed to fill an un-expired term shall serve for the remainder of that term. Members may continue to serve until re-appointed or replaced. Members may serve not more than two consecutive full terms;

B. Each member representing a public agency, shall be designated by the director of that department, and shall serve at the pleasure of the Mayor; and

C. Ex officio members shall serve at the pleasure of the Mayor.
VII. COMMITTEE COORDINATOR: ROLES AND RESPONSIBILITIES

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

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

VIII. AGENCY LIAISONS: ROLES AND RESPONSIBILITIES

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

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

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

A. Full Committee

1. A minimum of two-thirds of the members shall be present to constitute a quorum. Meetings of the full Committee will be for the purposes of:
   a. conducting case reviews, or assessing additional data from prior cases that have since become available;
   b. consideration of recommendations arising from available case reviews;
   c. preparation of the annual report; and
   d. any other business necessary for the Committee to operate or fulfill its duties.

2. Case review meetings of the full Committee shall be held monthly, if there are cases for review. (After procedures have been established and tested, the Committee may consider holding case review meetings bi-monthly, if practicable.) The full Committee may also convene monthly or ad hoc meetings as needed for additional case reviews, or for other specific purposes of the Committee, e.g., development of recommendations or preparation of the Annual Report.

3. The Committee shall conduct multi-disciplinary reviews of the events and circumstances surrounding the deaths of DWs as defined in Section II, in order to provide the data to fulfill the Purposes and Duties of the Committee as enumerated in Sections II and III, respectively.

4. Case reviews will occur at the next Committee meeting after the Committee receives notification of the fatality, or at the first meeting after sufficient materials are received for conducting the review. If the death is criminal in nature or under active criminal investigation, the review shall be preliminary, pending conclusion of the investigation and prosecution, or release by the prosecutor to conduct the review, at which time a comprehensive review shall be conducted.

5. The case review process shall include presentation of the case summary, followed by presentations of relevant information concerning the death by any agencies or persons involved with the DW, or investigating the event.

6. Following presentation of the facts, the Committee will discuss the case and any issues that it raises, guided by the following principles and questions:
   a. What factors or circumstances caused or contributed to the death? (This may include consideration of
systemic concerns related to the community, service and medical care providers, government supervision and regulation, and applicable or needed laws, procedures and regulations.)

b. What responses and investigations resulted from the death? (This includes whether all necessary agencies were notified and responded, and whether any corrective actions were instituted.)

c. Were the services, interventions and investigations concerning the DW appropriate and adequate for his/her needs? (In other words, did the systems and agencies provide and plan effectively for the DW?)

d. Were the staff involved with the DW adequately prepared, trained and supported to perform their duties correctly?

e. Was there adequate communication and coordination among the various entities involved with the DW?

f. Are the applicable statutes, regulations, policies and procedures adequate to serve the needs of the target population? If not, what changes to them are needed?

7. Based on the case discussion, the Committee shall formulate applicable recommendations as enumerated above in Sections III D and IV B and C(3), for further consideration and possible inclusion in the Annual Report.

B. Advisory Panel

1. An Advisory Panel shall be established for the purposes of addressing interagency and intergovernmental issues, especially those that concern coordination of service delivery to DWs, and implementing recommendations made by the Committee. This panel will be responsible for advising the Mayor on the ramifications of the recommendations, and at the Mayor’s direction, developing implementation strategies for the recommendations. The Advisory Panel shall also monitor the response to and implementation of the recommendations, address problems or obstacles to implementation, and report this to the full Committee.

2. The Advisory Panel shall meet semi-annually. The Advisory Panel may convene ad hoc meetings of its own volition, or at the request of the Committee or the Mayor, whenever necessary to fulfill its duties.

3. The Advisory Panel shall comprise the directors of relevant District Departments, who shall serve ex officio. The Advisory Panel shall, at a minimum, include the following agencies:
   (a) Department of Human Services (DHS)
   (b) Office of the Chief Medical Examiner (OCME)
   (c) Department of Health (DOH)
(c) Office of the Corporation Counsel (OCC)
(d) Metropolitan Police Department (MPD)
(e) Office of the Inspector General (OIG)

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

X. CASE REVIEW CRITERIA AND PROCEDURES

A. All deaths of DWs older than 18 years of age will be reviewed by the Committee. (Note: Deaths of DWs who are 18 years of age or less will be reviewed by the Child Fatality Review Committee.)

B. Factors of particular concern for review include:
   1. All violent or unexplained manners of death (i.e.- homicide, suicide, accident or undetermined), which include all deaths caused by injuries, including but not limited to:
      a. blunt trauma, including fractures
      b. burns
      c. asphyxiation or drowning
      d. poisoning or intoxication
      e. gunshot wounds
      f. stabbing or cutting wounds
   2. Abuse, either physical or sexual
   3. Neglect, including medical and custodial
   4. Malnourishment or dehydration
   5. Circumstances or events deemed suspicious

C. The Committee may, at its discretion, review groups of sudden, unexpected or unexplained deaths of DWs to examine aggregate data in order to address specific issues or trends.

D. DWs who live in facilities outside the District, or who die outside the District, will be subject to review by the Committee, and will be included in the Annual Report, both for statistical analysis and recommendations. The Committee members shall serve as liaisons to their counterparts in outside jurisdictions for the purpose of gathering information and obtaining documents (e.g.-police or autopsy reports) to complete the review.

XI. CASE NOTIFICATION PROCEDURES

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

B. Case notification reports should include for the affected DW:
   1. Demographic data (name, age/date of birth, race, gender)
   2. Address
   3. Parents/guardians
   4. Circumstances of the death (date, time, location, activities or risk factors, witnesses or sources of information)
   5. Agencies investigating the death
   6. History of involvement of government agencies or contracted service providers

C. MPD, DHS (OIC and MRDDA), DOH and OIG shall provide the Committee with copies of all death reports resulting from any investigation that is conducted on DWs. OCME shall provide the Committee with copies of all autopsy reports resulting from autopsies and death investigations conducted on DWs. These reports shall be provided within five (5) days after they are completed.

XII. NOTIFICATION OF PARTICIPANTS

Notification shall be provided in writing to all review participants two (2) weeks prior to the review. Notification shall include sufficient information for the case to be researched, the record identified and reviewed and adequate information related to the nature of the agency's involvement collected for presentation during the review meeting. Any agreed upon information shall be provided to the Committee Coordinator prior to the review.

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

XIII. RECORDS

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

A. Initial Data Form;
Final Report; and
C. Death Certificate.

XIV. CONFIDENTIALITY

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

B. Confidentiality Protocols

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

1. The Committee Coordinator shall be designated as the
   individual responsible for receiving and protecting all records.
2. During the notification and case selection process, every case
   will be assigned a number identifier and a record established.
   The full name of the DW and family shall be maintained in the
   case record at all times during the review planning process.
3. All case records shall be maintained in a locked file cabinet at
   all times unless in use by the Committee Coordinator or other
   designated staff of the Committee.
4. All records from other agencies/programs shall be obtained by
   or delivered directly to the Committee Coordinator. Once the
   necessary documents from the various member
   agencies/programs related to service delivery or interventions
   provided to the DW are received, they shall be maintained in the
   case record only.
5. A case summary shall be prepared for each case and stapled to
   the left inside cover of the file folder, for use by the Coordinator
   and chair of the review meeting.
6. No further duplication of documents is permitted.
7. Any documents distributed during the review shall only identify
   the DW by the Committee case number identifier.
8. Upon completion of the review of a case, all
   documents/information distributed shall be returned to the
   Committee Coordinator or other designated Committee staff.
   One (1) copy shall be maintained in the case record, along with
   a copy of the list of review participants, confidentiality
   statements for each review participant and the agenda.
remaining copies of the information distributed shall be shredded immediately after the review.

9. The final report from each review, describing the discussion, analysis of issues and recommendations, shall be prepared and included in the case record, which must be maintained in a secured file cabinet. These reports are not public documents and shall be maintained only in the Committee record. Persons who were involved with the family may review only the final report. Review may only occur in the Committee office and copying or faxing of these documents are not permitted.

10. All information contained in the Committee record identifying the DW, his/her family and any party or agency involved with the family at the time or prior to the death shall be destroyed three (3) years after the Annual Report has been issued.

11. Committee and Review Team members shall not disclose any case-specific information about the death (including the surrounding circumstances) derived from the review process to the press or any other third party.

12. The Committee Annual Report represents the only public document for distribution by the Committee. These Reports shall not contain any identifying information related to the DWs or their families.

C. Methods for ensuring that all information identifying third persons such as witnesses, complainants and agency/institution/program staff or professionals involved with the family are protected against disclosure are:

1. The same procedures established for DWs and their families above shall be followed for these entities.
2. Access to primary documents will be limited to the staff of the Committee and the chair of the review meeting.
3. Initials only will identify third persons in materials for distribution.

XV. RECOMMENDATIONS

A. Draft recommendations shall be developed by the Committee Coordinator based on issues raised during the reviews.

B. Draft recommendations shall be distributed to Departments and members for review and comment. Recommendations are finalized based on the comments received, including discussion at meetings of the Full Committee.

C. Final recommendations are incorporated into the Annual Report, and are forwarded to the Mayor. Interim recommendations may be forwarded to the affected entities for expeditious implementation, at the approval of the Mayor or his/her designee.

D. Representatives from agencies, institutions and programs may be invited to Full Committee meetings to present their plans for or progress made towards implementation of recommendations.
E. The Advisory Panel will address interagency and intergovernmental issues relating to implementation of recommendations, and will advise the Mayor or his/her designee regarding such concerns.

XVI. COMPENSATION

Committee members shall serve without compensation.

XVII. ADMINISTRATION

Appropriate administrative support, facilities and resources to ensure the effective operation of the Committee and the implementation of the requirements of The Mayor’s Order establishing this committee shall be provided under the direction of the Office of the Chief Medical Examiner. Expenses shall be obligated against funds designated for this purpose by the Department of Human Services or the Executive Office of the Mayor.

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

XVIII. EFFECTIVE DATE

This Order shall become effective immediately.

[Signature]
ANTHONY A. WILLIAMS
MAYOR

[Signature]
BEVERLY D. RIVERS
SECRETARY OF THE DISTRICT OF COLUMBIA
As used in this chapter:

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

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

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

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

(4) "Commitment" means the placement in a facility, pursuant to a court order, of an individual who is at least moderately mentally retarded at the request of the individual's parent or guardian without the consent of the individual or of an individual found incompetent in a criminal case at the request of the District; except it shall not include placement for respite care.
(5) "Community-based services" means non-residential specialized or generic services for the evaluation, care and habilitation of mentally retarded persons, in a community setting, directed toward the intellectual, social, personal, physical, emotional or economic development of a mentally retarded person. Such services shall include, but not be limited to, diagnosis, evaluation, treatment, day care, training, education, sheltered employment, recreation, counseling of the mentally retarded person and his or her family, protective and other social and socio-legal services, information and referral, and transportation to assure delivery of services to persons of all ages who are mentally retarded.

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

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

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

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

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

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

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

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

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

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

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

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

(13) "Facility" means a public or private residence, or part thereof, which is licensed by the District as a skilled or intermediate care facility or a community residential facility (as defined in D.C. Regulation 74-15, as amended) and also includes any supervised group residence for mentally retarded persons under 18 years of age. For persons committed or for whom commitment may be sought under § 7-1304.06a, the term "facility" may include a physically secure facility or a staff-
secure facility, within or without the District of Columbia. The term "facility" does not include a jail, prison, other place of confinement for persons who are awaiting trial or who have been found guilty of a criminal offense, or a hospital for the mentally ill within the meaning of § 24-501.

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

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

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

(A) Is at least mildly mentally retarded;

(B) Is charged with a crime of violence or sex offense;

(C) Has been found incompetent to stand trial, or to participate in sentencing or transfer proceedings; and

(D) Has been found not likely to gain competence in the foreseeable future.

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

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

(A) More to less structured living;

(B) Larger to smaller facilities;

(C) Larger to smaller living units;

(D) Group to individual residences;

(E) Segregated from the community to integrated with community living and programming; and/or

(F) Dependent to independent living.

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

(17A) "Mental illness" means a diagnosable mental, behavioral, or emotional disorder (including those of biological etiology) which substantially impairs the mental health of the person or is of sufficient duration to meet diagnostic criteria specified within the DSM-IV or its ICD-9-CM equivalent (and subsequent revisions) with the exception of DSM-IV "V" codes, substance abuse disorders, mental retardation, and other developmental disorders, or seizure disorders, unless those exceptions co-occur with another diagnosable mental illness.
(18) "Mental retardation advocate" means a member of the group of advocates created pursuant to § 7-1304.13.

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

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

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

(21) "Qualified mental retardation professional" means:

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

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

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

(D) A social worker with:

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

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

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

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

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

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

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

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

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

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

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

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


NOTES: SECTION REFERENCES. --This section is referenced in § 7-1303.12a.

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

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

For temporary amendment of section, see § 2(a) of the Civil Commitment of Citizens with Mental Retardation Legislative Review Emergency Amendment Act of 2002 (D.C. Act 14-454, July 23, 2002, 49 DCR 8096).
D.C. Code § 7-1301.03

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

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

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

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

ANALYSIS
Construction
Guardian

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

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

Cause of Death of Cases Reviewed in 2004

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

2001
1.* I. Closed Head Injury due to Motor Vehicle Accident, II. Hemothorax
2. Hypoxic encephalopathy due to Dislodgement of tracheostomy tube placed for treatment of pneumonia complicating trisomy 21
3.* Fluvoxamine Intoxication
4. Complications of Aspiration Pneumonia due to Cerebral aqueduct stenosis with hydrocephalus due to Probable old meningitis

2002
5. Acute Bronchopneumonia due to Severe coronary atherosclerosis
6. Blunt Impact Chest Trauma

2003
7.* I. ARDS due to Sepsis due to Aspiration Pneumonia, II. Cri du chat syndrome
8. Bronchopneumonia due to Alzheimer's Dementia due to Down Syndrome
9. Hypertensive Cardiovascular Disease
10. Gastric Necrosis and Perforation Associated with Hiatal Hernia
11. Septic complication following repair of incarcerated inguinal hernia
12. Hypertensive Cardiovascular Disease
13. Hypertensive Cardiovascular Disease

2004
14. Lung Cancer and its sequelae
15. Adenocarcinoma of the common bile duct
16. Metastatic Ovarian Carcinoma
17. Acute bronchopneumonia due to Hypertensive and Atherosclerotic Cardiovascular Disease
18. Complications following intravenous line insertion for hemodialysis for the treatment of end stage renal disease due to Hypertensive Cardiovascular Disease.
19.* Cause Opinion: Sepsis and its sequelae due to Pneumonia due to Ventilator dependence following bronchial mucous plug due to Kyphocoliosis and quadriplegia due to Cerebral Palsy of undetermined etiology. Contributing Conditions Opinion: Hypertensive, Valvular & Arteriosclerotic Cardiovascular Disease
20. Jurisdiction Not Accepted: In accordance with DC Official Code §5-1401 et. seq. (2001), and expiration of Mayor’s Order.
21. Acute bronchopneumonia due to Hypertensive and Atherosclerotic Cardiovascular Disease.
22.* Hydranencephaly and its sequela due to Perinatal event of undetermined etiology
23. Hypertensive and Arteriosclerotic Cardiovascular Disease
24. Intracerebral Hemorrhage due to Hypertensive Cardiovascular and Cerebrovascular Disease
25. Ischemic Heart Disease
26. Sepsis due to Endocarditis due to Disseminated infection from decubitis ulcers due to Limited mobility due to Complications of end stage renal disease due to Hypertensive and Arteriosclerotic Cardiovascular disease; Other significant conditions: Obesity
<table>
<thead>
<tr>
<th>FRC Recommendation</th>
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<tbody>
<tr>
<td><strong>01.013</strong> - a) The FRC recommends the need for improvement in case management records, b) and the need for a special budget for MRDDA Wards residing more than twenty (20) miles outside of the District, for special institutional needs.</td>
<td>a) In Progress. b) Implemented</td>
</tr>
<tr>
<td><strong>01.015</strong> - a) The FRC recommends that MRDDA institute a form for medication/dosages to be placed in the front of each District Ward resident. b) The FRC also recommended that a policy be developed to mandate that each District Ward receive annual health and dental assessments.</td>
<td>Implemented.</td>
</tr>
<tr>
<td><strong>01.017</strong> - The FRC recommends that the Quality Council (in the Health Regulations Administration of DOH) perform an exploration of what mechanism either exists or can be readily developed such that MRDDA can enforce better long-term documentation on their customers.</td>
<td>Pending Response</td>
</tr>
<tr>
<td><strong>01.108</strong> - The FRC recommends for the Committee to develop protocols regarding closure of MRDDA FRC cases.</td>
<td>Implemented.</td>
</tr>
<tr>
<td><strong>01.019</strong> - The FRC recommends that a request be made to DHS General Counsel to provide any information regarding the District’s policy on Do Not Resuscitate (DNR) order for MRDDA clients.</td>
<td>Implemented. See also Response to Recommendation 03-0147.1.</td>
</tr>
<tr>
<td><strong>01.0172.1</strong> - The FRC recommends that MRDDA develop a partnership with nursing facilities to ensure quality of care.</td>
<td>MRDDA has a comprehensive protocol that is activated for each consumer upon entering a nursing home. The consumer’s residential placement is reviewed by the MRDDA Human Rights Advisory Committee to assure that consumers’ rights are not violated prior to placement. Implemented.</td>
</tr>
<tr>
<td><strong>01.0172.2</strong> - The FRC recommends that MRDDA oversee the placement of consumers in skilled nursing facilities with a medical professional review of coordination of care and the appropriateness of health care services delivered.</td>
<td>Implemented.</td>
</tr>
<tr>
<td><strong>02.011</strong> - The FRC recommends that the KOBA Institute [or current contract agency] change the section of the investigative report from Recommendations to Suggestions, thereby reserving the term “recommendations: for the action the Committee formally proposes to address systemic issues or deficiencies.</td>
<td>Pending Response.</td>
</tr>
<tr>
<td><strong>02.012</strong> - The FRC recommends that a viable policy on the refusal of treatment be developed, which takes into account the issue of competency and the provision of appropriate support, such as that client can make a good informed decision, and not avoid or be denied medical care for life threatening conditions.</td>
<td>Pending Response.</td>
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<tr>
<td>• 02.015 - The FRC referred this case to the Quality Council.</td>
<td>Pending Response. Note: due to the disbanding of the Quality Council MRDDA will request the FRC to review this recommendation and determine whether it should be reissued, considered resolved, or rescinded.</td>
</tr>
<tr>
<td>• 02.021b - The FRC recommends that MRDDA conduct appropriate documentation and supervision [training] to meet the standards of the case management system.</td>
<td>Implemented.</td>
</tr>
<tr>
<td>• 02.021b - The Committee recommends that some guidelines be put in place at the residential facilities for the care of customer who for whatever reason are not able to participate in their day program.</td>
<td>Existing ICF/MR regulations, Medicaid Provider agreements and contracts contain standards that govern activities that should be made available to consumers who remain home from day programs due to illness or other reasons. Planned activities are also identified in the ISP to ensure that consumers are participating in their day programs or receiving active treatment when they are not in attendance.</td>
</tr>
<tr>
<td>• 02.024 - The FRC recommended that the Quality Council review the medical records of this customer, and make recommendations to the committee.</td>
<td>Pending Response.</td>
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<tr>
<td>• 02.374.3 - The FRC recommends that Adult Protective Service provide education to MRDDA staff and service providers on APS reporting requirements.</td>
<td>Implemented.</td>
</tr>
<tr>
<td>• 02.0279.1, 03-0147 - The FRC recommends that the Office of the Corporation Counsel (OCC) conduct a comprehensive assessment of the issue of DNR orders for MRDDA clients. OCC may assemble a working group as needed to accomplish this task.</td>
<td>Completed. Summary Response: The Office of the Attorney General for the District completed an in-depth review and determined that Do Not Resuscitate orders cannot be issued or authorized by the District or any of its agents.</td>
</tr>
<tr>
<td>• 02.028 - The Committee recommended that nursing and group homes should be staffed at adequate levels with properly trained personnel. The staff should monitor and document the care of MRDDA client and their adherence to internal quality assurance protocols on a routine basis. Group and nursing homes that do not have internal quality assurance measures should establish them. MRDDA should monitor compliance with these standards and report poor care and irregularities to the Health Regulation Administration.</td>
<td>Implemented.</td>
</tr>
<tr>
<td>• 02.0374.1 - The FRC recommends that MRDDA develop policies regarding coordination of care in acute care facilities including a process for reporting issues related to quality of care.</td>
<td>DHS currently has a protocol to address reporting issues related to quality of care, however, DHS has no jurisdiction or authority over acute care facilities. A protocol will be developed addressing MRDDA's response when customers are admitted to an acute care facility.</td>
</tr>
<tr>
<td>• 02.0374.2 - The FRC recommends that MRDDA develop procedures to address coordination of hospital discharge planning, pain management and follow up of end of life care.</td>
<td>Pending Response.</td>
</tr>
<tr>
<td>• 02.0569 - The FRC recommends that MRDDA review issues related to transportation of MRDDA clients, including incident reporting and the existence of and follow up to hospital discharge planning.</td>
<td>Pending Response. Note: Recommendation first issue - 04/29/03; Re-issued to MRDDA 02/23/05.</td>
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<tr>
<td>02.098 - Following review of this case, the Committee recommended the Quality Trust examine procedures for end-of-life care, including DNR orders and educate providers on appropriate procedures that will maintain the dignity of MRDDA clients.</td>
<td>Pending Response</td>
</tr>
<tr>
<td>02.1120.2 - The FRC recommends that the Health Regulation Administration review the records of J.B. Johnson Nursing Home to determine the quality of care that this home provides to MRDDA clients. The committee makes this recommendation due to J.B. Johnson’s failure, in this case to follow-up on medical issues, identify critical client health care needs, and adequately document the course of care.</td>
<td>In Progress</td>
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<tr>
<td>02.1331.1 - The Committee recommends that MRDDA explain the process and train the providers in the payment process for mental treatment for MRDDA customers, including Evans class members.</td>
<td>Implemented.</td>
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<tr>
<td>02.3693 - The FRC recommends that providers ensure and document that the direct care staff are both competent in and currently certified in first aid and CPR.</td>
<td>Implemented.</td>
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<td>02.3710 - The Committee recommends that the Medical Assistance Administration increase its oversight of physicians to ensure necessary services are provided by physicians directly to MRDDA residents.</td>
<td>Recommendation Declined.</td>
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<tr>
<td>03.0080 - The FRC recommends that IMIU follow up on the deficiencies of the provider’s performance as noted in Mortality Investigation.</td>
<td>Recommendation Declined.</td>
</tr>
<tr>
<td>03.0100.1 - The FRC recommends that death investigations shall include an interview of the primary care physician when healthcare and communication issues are identified</td>
<td>The DHS/IMIU Contract Manager for the investigation contract has communicated this recommendation to the contractor. The contractor will be monitored for compliance.</td>
</tr>
<tr>
<td>03.0100.2 - The FRC recommends that MRDDA incorporate the integration of End of Life issues into consumers’ person-centered plans as appropriate. MRDDA shall develop a training module on End of Life quality issues as part of the person-centered planning curriculum.</td>
<td>MRDDA’s Training Division offers comprehensive End of life training to community stakeholders, including those who participate in consumer’s IPS teams.</td>
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<tr>
<td>03.0100.3 - The FRC recommends that the Nursing Board promulgate regulations that establish acceptable ratios of LPN’s to ICF-MR facilities.</td>
<td>In Progress.</td>
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<td>03.0100.4 - The FRC recommends providers ensure each consumer’s quarterly medical review includes an assessment of prescribed medications. This must include a pharmacological review to determine whether the medications have any contra-indications with other medications, side effects, and/or food or dietary limitations that could impede the medication’s effectiveness or, if taken in conjunction with the medication, could cause a consumer’s diagnosis to worsen. The provider must ensure that the provider physician reviews, at least on a quarterly basis, the consumer’s medication record for, but not limited to, medication errors, duplicate prescriptions, interactions and contra-indications.</td>
<td>In Progress.</td>
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<td>03.0122 - The FRC recommends that MRDDA ensure that the oversight of clinical reviews</td>
<td>MRDDA is currently realigning its Clinical Services Division to meet the requirements of its Comprehensive Health Care Plan. The Plan required that</td>
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<td>and coordination of health care services on medically fragile individuals is</td>
<td>MRDDA and community providers oversee clinical reviews and coordinate health care services for all consumers served.</td>
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<td>conducted by the appropriate health care professionals. This will require that MRDDA assign adequate numbers of staff.</td>
<td></td>
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<td>03.0187.1 - The FRC recommends that DOH (MAA and HRA) and the OIG (MFCU)</td>
<td>MAA Response: “The responsibility for investigation of deaths rests with the HRA. The MAA will coordinate with HRA regarding the quality of services</td>
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<td>investigate the Washington Nursing Facility for concerns of neglect and failure to</td>
<td>rendered by providers who are reimbursed by DC Medicaid. If concerns are found related to the provision of care, or neglect then the fatality is cited and fined</td>
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<td>provide appropriate care, possibly causing or contributing to the deaths of patients.</td>
<td>depending upon the deficiency. The case will also be referred to the OIG and MPD if needed”. Declined by HRA Pending Response from OIG.</td>
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<td>03.0219, 03.00803 - The FRC recommends that ICF-MR’s shall ensure that the</td>
<td>Implementated.</td>
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<td>appropriate clinical professionals (including but not limited to: nurses, speech</td>
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<td>pathologists, occupational therapists, nutritionists, and physical therapists) are</td>
<td>Implementated.</td>
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<td>required to monitor mealtime protocols, physical management (such as safe feeding</td>
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<td>and appropriate positioning), dysphagia issues, and aspiration, or high-risk</td>
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<td>individuals requiring specialized services. This monitoring plan must be</td>
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<td>incorporated in the ISP</td>
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<td>03.0219.2 - The FRC recommends that provider agencies follow the DC Code and health</td>
<td>Implementated.</td>
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<td>regulations process when conducting intra-provider discharging and transferring of</td>
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<td>consumers, and should include coordination with case managers, appropriate</td>
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<td>advance notice to the entity receiving the consumer, and a transition plan that</td>
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<td>includes health care coordination, specific individualized support that the</td>
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<td>consumer may need, and training that the receiving entity’s staff may need to</td>
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<td>ensure a comprehensive transition for consumer and staff needs</td>
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<td>03.0278.1 - The FRC recommends that MRDDA develop a policy that requires providers</td>
<td>Response Pending.</td>
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<td>to identify health risk factors, coordination of care issues, and implement</td>
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<td>strategies to address and mitigate the risks identified into the Individual Service</td>
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<tr>
<td>Plan (ISP).</td>
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<td>03.0289.1 - The FRC recommends that for MRDDA customers placed outside of the</td>
<td>Implemented.</td>
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<td>District, a formal reporting protocol should be established between the Department</td>
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<td>of Human Services, Incident Management and Investigations Unit and the regulatory</td>
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<td>entity in the jurisdictions of the placements.</td>
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</tbody>
</table>
FRC Recommendation | Official Response
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03.0289.2 - The FRC recommends that MRDDA develop a plan for building provider capacity for alternative community residential placements in the least restrictive environment for individuals with mental retardation. | In Progress.

03.0289.3 - The Office of Corporation Counsel (OCC) and DHS General Counsel should conduct a legal review of the "affidavit of friend". The research is to address the validity of such documents, and the process in which one becomes an advocate to make medical decisions for MRDDA customers who are receiving services outside of the District of Columbia. | Response Received. Due to the length of this response from OCC it is available for review via written request to MRDDA FRC Committee.

03.0379.2 - The FRC recommends that MRDDA develop a general educational document highlighting healthcare coordination issues in serving MRDDA customers, to be distributed to the relevant healthcare community. | Pending Response.

03.0459.1 - The Committee recommends that MRDDA send a letter to providers requiring that they develop an Emergency Medical Care Information Sheet to include: Medications; Clinical Diagnosis list; and Contacts for the purpose of obtaining consent to accompany consumers for routine and emergency medical visits to be left with medical providers. This form should be regularly updated. | Pending Response.

04.0190 - The FRC recommends that MRDDA provide training on coordinated services and support for senior (elderly) MRDDA consumers | Implemented

04.0432 - The FRC recommends that OCME investigators should be made aware of medications and other co-existing disorders by DHS/IMIU via the DHS/MRDDA Fatality Review Form | Pending Response.

04.0520 - The FRC recommends that MRDDA continue plans for training regarding risk factors and to use the Board of Nursing as experts and support on MRDDA’s efforts. | Implemented

04.0408 - The FRC recommends that all health care issues are incorporated in the ISP in a coordinated plan of care. | Implemented

04.0408.1 - The FRC recommends that MRDDA follow up with the Providers Medical Passport System Review Form | Implemented

04.0531 - The FRC recommends that IMIU investigation report (via Columbus) includes a review of day programs that offer medical support during the day. MRDDA shall provide a list of all Medical Day providers to IMIU | Pending Response.

04.0531.1 - Initial Recommendation Dated 11/19/04 - The FRC recommends that this body report the practices of this provider to the Medical Board. | Revised Recommendation Dated 01/28/05 - This recommendation is being revised to read: The FRC recommends that MRDDA send a letter to VOCA regarding the practices of this physician with a carbon copy to the Medical Board and OIG. | Pending Response.

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1 The Columbus organization is a contractor with the District of Columbia Department of Human Services. This organization conducts mortality investigations for deceased persons with mental retardation and developmental disabilities.
<table>
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<tbody>
<tr>
<td>04.0531.2 - The FRC recommends that MRDDA send a reminder to the provider community regarding MRDDA’s Medical Care Protocols.</td>
<td>Pending Response</td>
</tr>
</tbody>
</table>