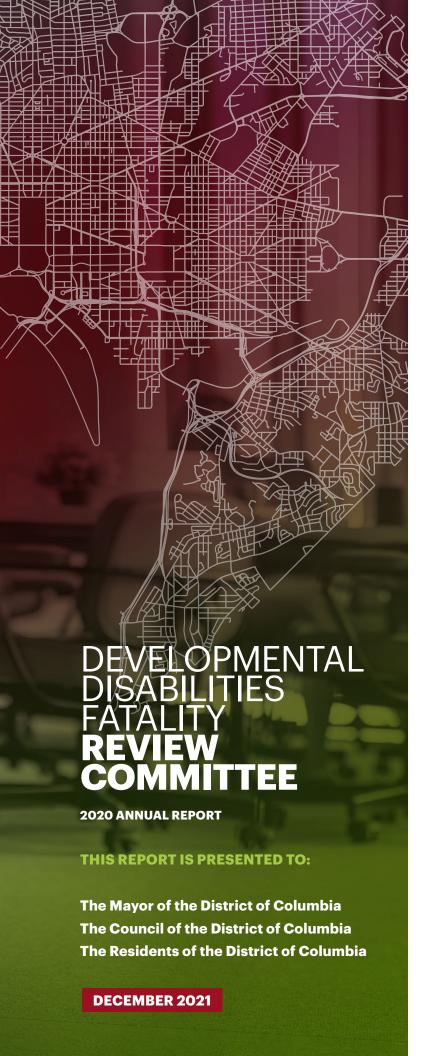


# MISSION OF THE DDFRC

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





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# KEY FINDINGS FROM **DEATHS REVIEWED FROM 2020**

During the calendar year 2020, the Committee reviewed 33 fatalities of DDS individuals who died between years 2019 through 2020. The following is a summary of the data included in the 2020 Annual Report.

**81.8%** 

Of the fatalities reviewed, twenty-seven (81.8%) were attributed to natural causes

**54.5%** 

Eighteen (54.5%) of the individuals were over the age of 60.

**30.3%** 

Ten (30.3%) of the individuals were over the age of 70.

**84.8%** 

Twenty-eight (84.8%) of the individuals were African American.

Average age at death was 57 years.

# **GREETINGS FROM** THE CHIEF MEDICAL **EXAMINER**

As an appointed member of the **Developmental Disabilities Fatality Review** Committee (DDFRC), I know the District of Columbia's extraordinary commitment to its' residents with intellectual and developmental disabilities.

The COVID-19 pandemic presented a challenge to our community's efforts to protect this population. With its mission to reduce the number of preventable deaths among this population, the DDFRC continued to convene to address the challenges for this population and their caretakers.

The DDFRC members are our public servants, all multidisciplinary subject-matter experts. This opportunity to look retrospectively at past events and develop recommendations for systemic improvements is unique. We are appreciative of the work of the DDFRC.

We proudly present the 2020 Developmental Disabilities Fatality Review Committee Annual Report. We hope that this report will help to inform our public servants and community advocates to improve outcomes for our most vulnerable residents.



Sincerely,

Francisco J. Diaz

Francisco J. Diaz, MD, FCAP

Chief Medical Examiner Office of the Chief Medical Examiner Washington, DC.

# INTRODUCTION

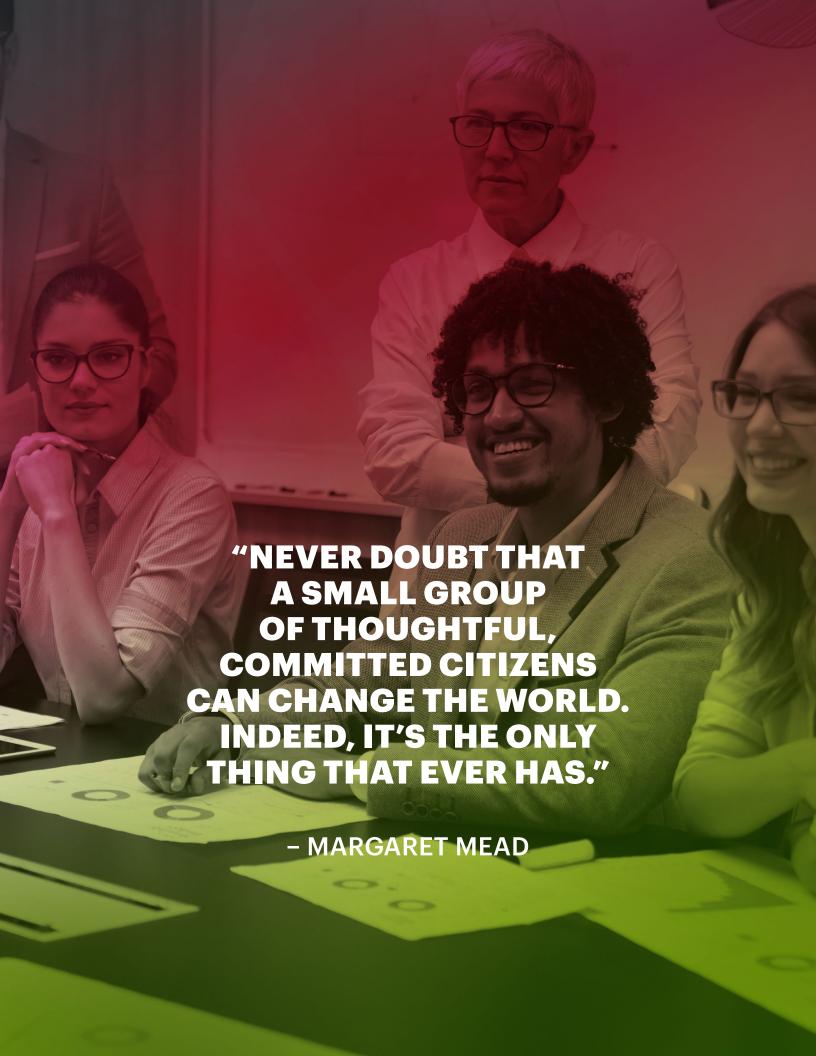
The 2020 Annual Report is a summary of the work performed by the Developmental Disabilities Fatality Review Committee (DDFRC) during calendar year 2020. It provides a synopsis of the total population identified by the Committee annually as meeting the criteria for review and the data that is specific to the 33 fatalities reviewed during the year.

The DDFRC was re-established by Mayor's order in September 2009, under the auspices of the Office of the Chief Medical Examiner (OCME). It is a multidisciplinary, multi-agency effort established for the purpose of conducting retrospective reviews of relevant service delivery systems and the events surrounding the deaths of District wards and residents 18 years of age and older who received services and/or supports from DDS. One goal of the DDFRC is to identify trends and make recommendations to improve the supports and services received by the citizens of the District of Columbia.

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

One of the primary functions of the DDFRC involves the collection, review, and analysis of individuals' death-related data 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 the individual's death that includes a summary of the forensic autopsy report; the individual'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 individual's quality of life. Another important result of this process is the recognition of best practices and the provision of recommendations to create and implement these practices as a critical component of systemic change.



# SECTION I: SUMMARY OF CASE REVIEW FINDINGS

This report addresses the circumstances surrounding the deaths of District residents diagnosed with an intellectual and developmental disability and who received services through DDS.

# Eligibility criteria used by DDS to identify persons with intellectual and developmental disabilities are as follows:

- Psychological evaluation, based on one or more standardized test, that documents sub-average general intellectual functioning IQ score of 69 or below, formal assessment of adaptive behavior or other supporting documentation of adaptive behavior deficits or developmental delays manifested before the age of 18 years, indicating that impairments in cognitive adaptive functioning continue into adulthood.
- Documentation that verifies the diagnosis of an intellectual disability prior to the age of 18 occurred, this includes school records/transcripts, medical records, or social history, if available.

## **TOTAL FATALITIES**

Table 1 illustrates the total number of individuals served by DDS for a ten-year period, the total number of fatalities annually, and the percentage of individuals who died. During calendar years 2011 through 2020, the number of consumers served ranged from 2,187 to 2,540 while the number of DDS deaths during the same ten-year span ranged from 28 to 38 annually. Percentage of deaths has remained consistent. **See Table 1.** 

In 2020, the DDFRC reviewed the deaths of thirty-three (33) adult individuals who were served by the DDA. Table 2 indicates the total number of cases reviewed by the DDFRC since 2016. **See Table 2**.

**TABLE 1** District of Columbia DDS Population and Deaths 2011 to 2020

YEAR	DDS POPULATION	NUMBER OF DDS POPULATION DEATHS	PERCENTAGE
2011	2187	31	1.40%
2012	2227	37	1.70%
2013	2248	33	1.50%
2014	2284	35	1.50%
2015	2317	34	1.50%
2016	2397	35	1.50%
2017	2452	38	1.50%
2018	2540	28	1.10%
2019	2493	33	1.30%
2020	2471	33	1.30%

**TABLE 2** Number of Fatalities Reviewed Per Year

YEAR OF REVIEW	NUMBER OF FATALITIES REVIEWED
2016	35
2017	39
2018	28
2019	33
2020	33



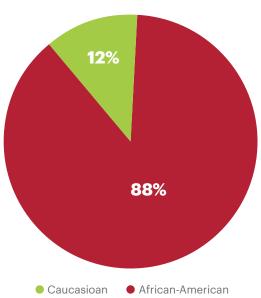
## DEMOGRAPHICS

## **RACE OF DECEDENTS**

Consistent with the overall DDS population and with previous DDFRC reviews, most of the DDFRC cases reviewed involved African American decedents (n=29, 88%). As seen in **Figure 1**, the remaining four (12%) decedents were Caucasian. No decedents identified as any other race.

**Table 3** shows the number of decedents of each race over the last four years. There is a consistent trend in the higher percentage of deaths of African Americans over other races. There is also a decreasing trend in deaths of Caucasians.

FIGURE 1
Race of Decedents (N=33)



**TABLE 3** Race

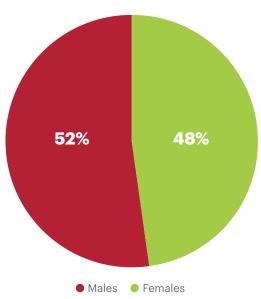
YEAR OF REVIEW	AFRICAN AMERICAN	CAUCASIAN	OTHER
2017	30	8	1
2018	19	7	2
2019	29	4	0
2020	29	4	0

#### **GENDER OF DECEDENTS**

Of the 33 fatalities reviewed, 17 (51.5%) DDFRC decedents were male and 16 (48.5%) were female. **See Figure 2.** 

As seen in **Table 4**, a review of the last 4 years indicates the percentage of decedents who were male ranged from 51% - 74% per year. While there are consistently more deaths among males, the difference between males and females is shrinking.

FIGURE 2
Gender of Decedents (N=33)



**TABLE 4** Gender

YEAR OF REVIEW	FEMALE	MALE
2017	10	29
2018	11	17
2019	15	18
2020	16	17

#### **AGE OF DECEDENTS**

Based on fatalities reviewed, the relationship between age and mortality has historically demonstrated the mortality rate increasing as individuals begin to age. As Figure 3 illustrates, most decedents were over the age of 61. During 2020, there were only three fatalities in which the decedent was under 31 years of age and three who were between the ages of 31 and 40. The average age at death over the last four review periods ranged from 56 – 64.8.

**Table 5** depicts the average age at death (or life span) and age range for each year since 2017. During 2020, the average age of the 33 decedents at the time of death was 57 years. The CDC currently reports that the average age of death for the total US population (with and without disabilities) was 78.7 years in 2018 and has declined to 77.8 in 2019. Since 2019, this is 20.8 years more than the DDFRC sample.

# EFFECT OF GENDER AND RACE OF DECEDENTS ON AGE AT DEATH

The data were examined to determine the effect of gender and race, if any, on the age of the decedents. As depicted in **Figure 3**, there is a small difference (2.7 years) between the age of the female decedents (n=16) and the male decedents (n=17).

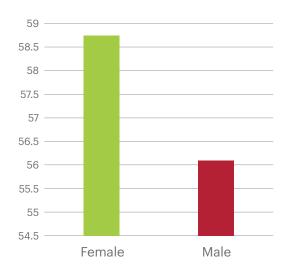
**Figure 4** shows that, the race of the decedents was also a factor in the age at death. Caucasian decedents (n=4) had the longest average lifespan, while African Americans (n=29) had the shortest. Although this is consistent with the overall statistics for the US (CDC, 2017), the disparity between the DDFRC sample (9.5 years) is much greater than in the US population overall (3.75).

**TABLE 5** Range of Age and Average Age at Death

YEAR OF REVIEW	AGE RANGE	AVERAGE AGE AT DEATH
2017	20 - 84	56.1
2018	29 - 93	64.8
2019	29 - 83	59
2020	23 - 80	57

## FIGURE 3

Effect of Gender on Age at Death (N=33)



### FIGURE 4

Effect of Race on Age at Death (N=33)

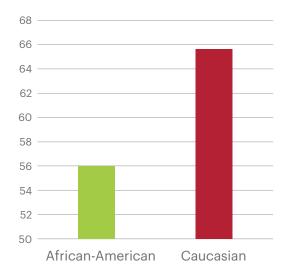


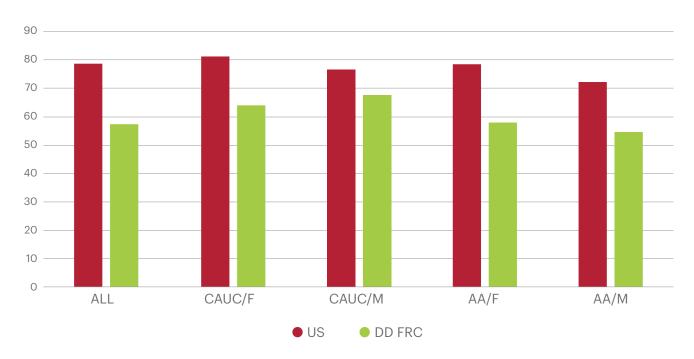


Figure 5 depicts the age at death of the decedents based on race/gender combinations. There appears to be an interaction between race and gender as African American females had a longer lifespan than African American males, however Caucasian males had a longer lifespan than Caucasian females. Due to the small number of

Caucasian deaths (2 female and 2 male) this conclusion may not be meaningful.

Table 6 shows the average age of decedents by gender and race (N=33) in 2020 DDFRC review sample.

# FIGURE 5 Average Age at Death by Race/Gender (N=33)



**TABLE 6** Average Age at Death in DDFRC Sample

	TOTAL	AFRICAN AMERICAN	CAUCASIAN
Males	56.1 years (n=17)	54.6 years (n=15)	67.5 years (n=2)
Females	58.8 years (n=16)	58 years (n=14)	64 years (n=2)
Total Sample	57.4 years (n=33)	56.2 years (n=29)	65.8 years (n=4)
2020	29	4	0



#### **TYPE OF DDS RESIDENCE**

Quality of care in various types of residences can be measured in many ways, one of which is by looking at mortality rates for each residential type.

The 33 fatalities reviewed involved individuals who resided in their natural homes or community-based placements where their specialized needs could be met. As shown in Figure 6, many deaths involved decedents living in an Intermediate-Care Facility (ICF) home (33%) or a Supported Living home (37%). Five people lived in their natural home and three in a Residential Habilitation home. The remaining decedents lived in a Skilled Nursing Facility (n=1) or a Long-Term Acute Care home (n=1).

### **LOCATION OF FATALITY**

The fatality reviews revealed that the deaths occurred in different locations including hospitals, nursing facilities, and residential placements.

As depicted in Figure 7, of the 34 decedents, most individuals (23.5%) died during a hospital admission, or at their place of residence (41.2%), and six (17.6%) were pronounced dead in a hospital emergency department. Three people died in hospice (8.8%) and two in a nursing home (5.9%). One person died at the home of a friend.

FIGURE 6 Type Of DDS Residence

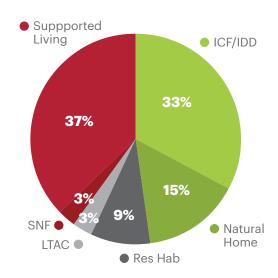
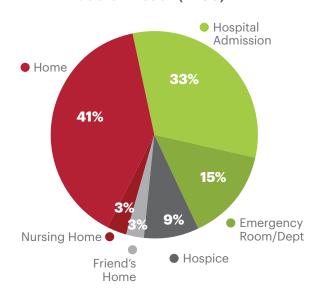


FIGURE 7 Place Of Death (n=33)



# MOBILITY AND MEALTIME ASSISTANCE

Mobility and impairments with food intake among individuals with intellectual and developmental disabilities are recognized problems that place individuals at higher risk of morbidity and mortality. The independent investigative reports provided to the DDFRC include detailed information related to these risks and the Committee considers these factors as part of the case evaluation process.

As depicted in **Table 7**, based on the 33 fatalities reviewed, 12 (36.4%) individuals were on a regular textured diet while seven (21.2%) required the use of a Gastronomy tube for most of their food intake. Decedents who were allowed some "pleasure eating" were categorized as having a G-tube. Pureed or "mechanical soft" foods were required for the remaining 14 (42.4%) individuals.

In **Table 8**, the data show the type of mobility for DDFRC decedents over that past four years. In 2020, 12 (36.4%) decedents required the use of a wheelchair, and nine (27.3%) required support (gait belt, walker, etc.). Twelve people (36.4%) were mobile without support, an increase over last year.

#### **MENTAL HEALTH DIAGNOSES**

The mortality investigative report provides information regarding the diagnosis of individuals with mental health diagnoses as well as the individuals' cognitive and adaptive level of functioning. Twenty-two of the 33 DDFRC individuals (66.7%) had one or more mental health diagnoses, whereas 33.3% (11) had none. Nearly one-third of the decedents (33.3%) had two or more mental health diagnoses. See **Table 9.** 

### **TABLE 7** Food Textures

TEXTURES	2017	2018	2019	2020
Regular	24	7	8	12
Pureed/Mechanical Soft	4	12	12	14
G-tube Dependent	11	9	13	7

## **TABLE 8** Individual's Method of Mobility

METHOD OF MOBILITY	2017	2018	2019	2020
Mobile without Support	12	0	8	12
Mobility Requiring Support	10	12	5	9
Mobility Requiring Wheelchair Use	17	16	20	12

# TABLE 9 Mental Health Diagnoses of Decedents Reviewed in 2020

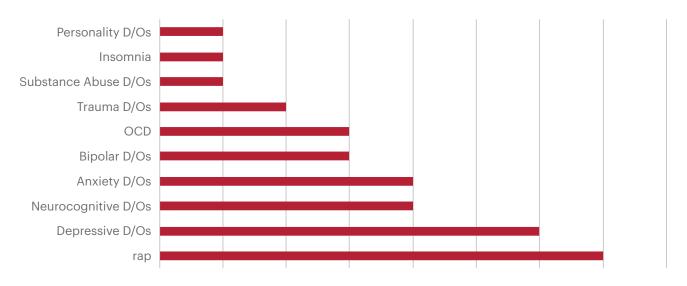
MENTAL HEALTH DIAGNOSES	NUMBER OF DECEDENTS	PERCENT OF DECEDENTS
0	11	33.3%
1	7	21.2%
2	9	27.3%
3	2	6.1%
4 or more	4	12.1%

Mental Health diagnoses ranged from Autism to Anxiety Disorders to Psychotic Disorders. Figure 8 below represents the category of diagnoses, rather than the individual diagnoses. The most common diagnosis category was disruptive/impulse control/conduct disorders with seven of the 20 decedents (31.8%) who had at least one diagnosis having such a diagnosis. Overall, this number represents 21% of the 33 decedents reviewed by DDFRC in 2020. Six decedents were diagnosed with a depressive disorder.

Table 10 provides the individual's level of functioning as related to intellectual disability as provided in the mortality investigative report. Cognitive functioning is the individuals' multiple mental capabilities Adaptive functioning refers to the individuals' development of life skills.

- Profound Intellectual Disability: Individuals require high levels of supervision and structure with activities of daily living.
- Severe Intellectual Disability: Individuals may have some self-care and communication skills however will also need supervision and a structured living environment.
- Moderate Intellectual Disability: Individuals may require some supervision and can perform successfully in a supervised living environment.
- Mild Intellectual Disability: Individuals can perform independently with the appropriate community and social support.

## FIGURE 8 Mental Health Diagnoses



Number of Decedents

**TABLE 10** DDFRC Individual's Cognitive and Adaptive Level of Functioning

LEVEL OF FUNCTIONING	COGNITIVE	ADAPTIVE
Profound	11	12
Severe	7	11
Moderate	12	7
Mild	3	3

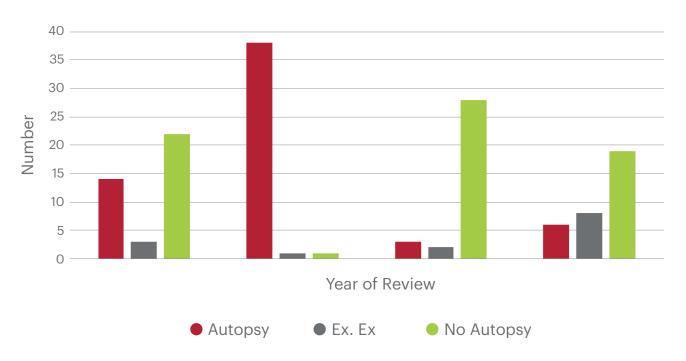
# MANNER AND CAUSE OF DEATH

## **AUTOPSIES**

**Figure 9** depicts the number of autopsies conducted per year for the past four years. Of the 33 deaths reviewed in 2020, six (18.2%) had an autopsy completed. Eight (2.2%) had an External Examination only. Nineteen (57.6%) decedents did not have an autopsy or external exam. The

determination of when an autopsy is performed is made by the attending pathologist. An autopsy may be done when there are potential competing causes of death, when the death is sudden or unexpected, when the manner of death is determined to be other than a natural type of death, or when the examination is mandated by law.

# **FIGURE 9** Autopsies Conducted



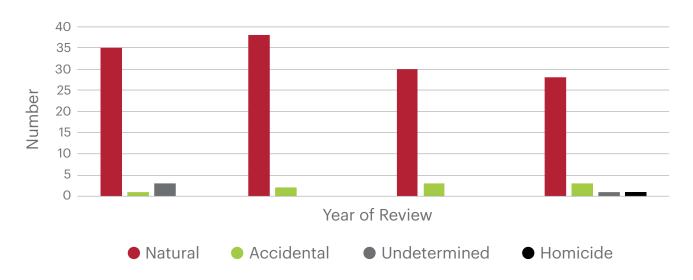


#### MANNER OF DEATH

**Figure 10** depicts the manner of death provided to DDFRC for the past four years. There are five manners of death including homicide, suicide, accident, natural, and undetermined. The manner of death, as determined by the forensic pathologist, is an expert opinion based on the

death investigation and known medical facts concerning the circumstances leading to and surrounding the death, in conjunction with the findings at autopsy and laboratory tests. During this review period, 84.8% of the 33 fatalities of the 2020 DDFRC individuals were determined to be natural deaths. Three (9.1%) were ruled accidental, one a homicide (3%) and one (3%) undetermined.

#### FIGURE 10 Manner of Death



#### **CAUSE OF DEATH**

Table 11 provides a list of the causes of death across the past four years and those associated with the 33 fatalities reviewed in 2020. Most of the DDFRC individuals died of cardiovascular disease (36.4%), followed by respiratory disease (21.2%). Three (9.1%) individuals died because of cancer. Two people each (6.1%) died of neurological system disease, trauma, gastrointestinal system issues, and sepsis. The remaining three people died of multisystem organ failure, renal disease, and drug overdose. It is interesting to note a decrease in deaths related to respiratory disease and an increase in deaths related to cardiovascular disease resulting in a change in the leading cause of death.

## **TABLE 11** Causes of Death

CAUSE OF DEATH	2017	2018	2019	2020
Cardiovascular System Disorder	15	16	8	12
Respiratory Disease	8	5	12	7
Cancer	4	1	4	3
Neurological System Disease	0	0	0	2
Trauma	1	0	3	2
Gastrointestinal System	2	2	1	2
Sepsis	0	0	0	2
Multi-system Organ Failure	1	0	0	1
Renal Disease	0	0	0	1
Drug Overdose	0	0	0	1
Infectious Disease	3	3	4	0
Cardiopulmonary System Disorder	0	0	1	0
Other	0	1	0	0
Genetic Disorder	4	0	0	0
Diabetes	1	0	0	0



# APPENDIX A GLOSSARY OF TERMS

#### **AUTOPSY REPORT**

A detailed report consisting of the autopsy procedure, microscopic and laboratory findings, a list of diagnoses, and a summary of the case.

#### **CRF/ID**

Community Residential Facility for individuals diagnosed with an intellectual disability

#### **GROUP HOME**

Licensed homes for persons with intellectual disabilities that range in size from four (4) to eight (8) customers

#### HOSPICE

A program or facility that provides special care for people who are near the end of life and for their families

#### ICF/I1D

A licensed residential facility certified and funded through Title XIX (Medicaid) for consumers diagnosed with an intellectual disability. Consumers receive 24-hour skilled supervised care.

#### **LEVEL OF DISABILITY**

Cognitive and adaptive impairment ranging from mild to profound

#### LIFE EXPECTANCY

The average expected length of life; the number of years somebody is expected to live

#### **MEDICAID WAIVER**

Provides rehabilitative, behavioral, and medical supports to individuals with intellectual and developmental disabilities in residential community, and private home settings.

#### **NATURAL HOME**

Consumers residing in the home of a parent, family members or independently

#### **NEUROLOGICAL CONDITIONS**

Disorders of the neuromuscular system (the central, peripheral, and autonomic nervous systems, the neuromuscular junction, and muscles)

#### **NURSING HOME**

A long-term healthcare facility that provides full-time care and medical treatment for people who are unable to take care of themselves

#### **SKILLED CARE**

An institution (or a distinct part of an institution) that is primarily engaged in providing skilled nursing care and related services for residents who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons

#### **SPECIALIZED HOME CARE**

A private home living environment for three (3) or less individuals (also includes foster care)

#### SUPERVISED APARTMENTS

Typically a living arrangement for one to three customers with intellectual disabilities, 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

# APPENDIX B CAUSES OF DEATH

## **CAUSES OF DEATH - 2020 DDFRC DEATHS REVIEWED**

The table in this section provides the causes of deaths in cases reviewed by the DDFRC in 2020.

# **TABLE A1** Deaths Reviewed that Occurred in 2020

AGE	RACE	SEX	CAUSE OF DEATH	MANNER OF DEATH
28	AA	М	Complications of non-traumatic seizure disorder	Natural
40	AA	М	Complications of nontraumatic small bowel obstruction	Natural
53	AA	F	Complications of Down Syndrome with significant conditions of diabetes mellitus and static encephalopathy	Natural
60	AA	F	Hypertensive and atherosclerotic cardiovascular disease	Natural
78	AA	М	Metastatic rectal adenocarcinoma with metastasis to liver and lung with a significant condition of hypertension	Natural
24	AA	M	Gunshot wound to the neck	Homicide
64	AA	F	Hypertension and CHF	Natural
80	AA	М	Hypertensive and Atherosclerotic CVD; non-traumatic sei-zure disorder	Natural
56	AA	F	Sudden cardiac dysrhythmia	Natural
67	AA	М	Metastatic prostate cancer	Natural
52	С	F	Multisystem organ failure	Natural
73	С	М	Complications of fracture of right hip d/t a fall	Accidental
71	AA	М	Intracerebral hemorrhage and hypertension	Natural
72	AA	F	Bowel infarction due to cecal volvulus with other significant conditions of hypertensive atherosclerotic cardiovascular disease and Pica	Natural
57	AA	M	Ethanol and Fentanyl Intoxication	Accidental



**PAGE 1** 

#### GOVERNMENT OF THE DISTRICT OF COLUMBIA

#### ADMINISTRATIVE ISSUANCE SYSTEM

Mayor's Order 2009-225 December 22, 2009

SUBJECT:

Revitalization - District of Columbia Developmental Disabilities Fatality

Review Committee

ORIGINATING AGENCY: Office of the Mayor

By virtue of the authority vested in me as Mayor of the District of Columbia by section 422(2) of the District of Columbia Home Rule Act ("Home Rule Act"), as amended, 87 Stat. 790, Pub. L. No. 93-198, D.C. Official Code § 1-204.22(2) and (11) (2001), it is hereby **ORDERED** that:

#### I. ESTABLISHMENT

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

#### II. PURPOSE

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

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

#### III. DUTIES

The duties of the Committee shall include:

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

#### IV. FUNCTIONS

The functions of the Committee shall include:

A. Developing and issuing procedures governing its operations within ninety (90) days of the effective date of this Mayor's Order. To the extent such procedures already have been developed, issued and implemented the Committee may continue to operate under those procedures. The procedures shall include, at a minimum, the following:

PAGE 3

- 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.

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#### 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 (bimonthly), 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:

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

## X. CASE REVIEW CRITERIA AND PROCEURES

#### A. Case Review Criteria

The Committee shall review the following deaths:

- 1. All deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability shall be reviewed by the Committee. Factors of particular concern for review include:
  - a. All violent or sudden/unexplained manners of death (i.e., homicide, suicide, accident or undetermined), which include all deaths caused by injuries or illness, including but not limited to:
    - i. Fractures;
    - ii. Blunt trauma;
    - iii. Burns;
    - iv. Asphyxia or drowning;
    - v. Poisoning or intoxication;
    - vi. Gunshot wounds;
    - vii. Stabbing or cutting wounds;
    - viii. Falls;
    - ix. Sepsis;
    - x. Gastrointestinal blockages; or
    - xi. Seizures.
  - b. Abuse, either physical or sexual;
  - c. Neglect, including medical and custodial;
  - d. Malnourishment or dehydration; and
  - e. Circumstances or events deemed suspicious.
- 2. The Committee may, at its discretion, review groups of sudden, unexpected or unexplained deaths of District residents with an intellectual disability and/or a

- qualifying developmental disability without regard to age, in order to examine aggregate data to address specific issues or trends.
- 3. The deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability who live in facilities, homes or other living arrangements outside of the District, or who die outside of the District, will be subject to review by the Committee, and will be included in the annual report, both for statistical analysis and recommendations. The Coordinating Staff shall serve as a liaison to his or her counterparts in foreign jurisdictions for the purpose of gathering information and obtaining documents (e.g., police or autopsy reports) to complete the review.

#### **B.** Case Review Procedures

- 1. Case review meetings shall be multi-disciplinary and shall occur within three months of receiving the mortality/fatality report or other sufficient materials required to examine the events and circumstances surrounding the death and to fulfill the purposes and duties of the Committee as enumerated in Sections II and III of this Order. The review may be preliminary, pending conclusion of the investigation and prosecution or release by the prosecutor to conduct the review, at which time a comprehensive review shall be conducted.
- 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?

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4. Based on the case discussion, the Committee shall formulate applicable recommendations as enumerated above in section III.d and section IV.a and b.3, for further consideration and possible inclusion in the annual report.

### XI. CASE NOTIFICATION PROCEDURES

- A. District agencies and service providers contracted by the District to serve District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability shall provide written notification to the Committee within twenty-four (24) hours of any death of a District resident over the age of 18 years with an intellectual disability and/or a qualifying developmental disability, or within twenty-four (24) hours of becoming aware of such a death. The sources of notifications will include but are not limited to the:
  - 1. Department on Disability Services (DDS), Developmental Disabilities Administration (DDA);
  - 2. Office of the Chief Medical Examiner (OCME);
  - 3. Metropolitan Police Department (MPD);
  - 4. Office of the Attorney General (OAG);
  - 5. Department of Health (DOH); and
  - 6. Department of Health Care Finance (DHCF).
- B. Case notification reports should include:
  - 1. Demographic data (i.e. name, age/date of birth, race, gender);
  - 2. Address:
  - 3. Parent/guardian;
  - 4. Circumstances of the death (i.e. date, time, location, activities, risk factors, witnesses or sources of information); and
  - 5. Agencies investigating the death.
- C. MPD, DDS, DOH and DHCF shall provide the Committee copies of all death reports resulting from any investigations that are conducted concerning the population covered by the Order (see Section X: Case Review Criteria). The OCME shall provide the Committee with a copy of all autopsy reports resulting from autopsies and death investigations conducted for District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability. These reports shall be provided within five (5) days after they are completed.

## XII. NOTIFICATION OF PARTICIPANTS

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

- the review meeting. Any agreed information shall be provided to the Committee staff support prior to the review.
- **B.** Similar written notification shall be provided to all independent and/or community individuals invited to the review meeting. These may include experts from various relevant disciplines or service areas.

#### XIII. RECORDS

All records and reports shall be maintained in a secured area with locked file cabinets. One (1) year after the annual report has been distributed, all supporting documentation in each fatality record shall be destroyed. The only material that will be maintained in a fatality record will be the following:

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

#### XIV. CONFIDENTIALITY

- A. A key tenet of the Committee is the necessity for keeping confidential information obtained by, presented to and considered by the Committee, consistent with the confidentiality provisions of section 512 of the Mentally Retarded Citizens Act (D.C. Official Code § 7-1305.12) (2008 Repl.).
- **B.** Any information gathered in preparation for or divulged during Committee reviews shall not be disclosed except as provided in subsection d of this section and applicable law, including the Freedom of Information Act of 1976, effective March 29, 1977, D.C. Law 1-96, D.C. Official Code § 2-531 et seq. (2006 Repl.).
- C. All participants in the Committee proceedings shall be required to sign a confidentiality statement prior to all Committee case review meetings and prior to general meetings where any specific case is discussed. Case-specific information distributed during any meeting shall be collected at the end of each review. Any participant who is not willing to sign a confidentiality statement or to abide by the confidentiality requirements shall not be allowed to participate in case review or general meetings.
- **D.** Methods for ensuring that all information identifying third persons such as witnesses, complainants, agency, institution, or program staff or professionals involved with the family are protected against disclosure are:
  - 1. The same procedures established for District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability and their families above shall be followed for these entities.
  - 2. Access to primary documents will be limited to the staff of the Committee and the chair of the review meeting.

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3. Initials only will identify third persons in materials for distribution.

#### RECOMMENDATIONS XV.

- 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. <u>RESCISSIONS</u>

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.

DRIAN M. FENTY

ATTEST

STEPHANIE D. SCOTT

SECRETARY OF THE DISTRICT OF COLUMBIA

# **ACKNOWLEDGMENT**

We wish to acknowledge the dedication and unwavering support of the public servants, private agency/program representatives, university, and community volunteers who serve as members of the District of Columbia Developmental Disabilities Fatality Review Committee.

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.

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.





# DEVELOPMENTAL DISABILITIES FATALITY REVIEW COMMITTEE

**2020 ANNUAL REPORT** 





Office of the Chief Medical Examiner

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