District Of Columbia
Developmental Disabilities Fatality Review Committee

2019 ANNUAL REPORT

OFFICE OF THE CHIEF MEDICAL EXAMINER
DISTRICT of COLUMBIA

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DISTRICT OF COLUMBIA DEVELOPMENTAL DISABILITIES FATALITY REVIEW COMMITTEE

2019 ANNUAL REPORT

MISSION:

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

PRESENTED TO:

The Honorable Muriel Bowser, Mayor, District of Columbia

The Council of the District of Columbia

March 2021

TABLE OF CONTENTS

EXECUTIVE SUMMARY ... 4

INTRODUCTION ... 6

SECTION I: SUMMARY OF 2018 CASE REVIEW FINDINGS ... 8

Demographics ... 10

Race ... 10

Gender ... 11

Age ... 11

Age, Race, and Gender ... 13

Type of Residence ... 14

Location of Fatality ... 14

Mobility and Mealtime Assistance ... 15

Diagnoses ... 15

Manner and Cause of Death ... 17

Autopsies ... 17

Manner of Death ... 18

Cause of Death ... 18

SECTION II: DDFRC TRENDS AND RECOMMENDATIONS ... 10

APPENDICES ... 24

Appendix A: Glossary of Terms ... 25

Appendix B: Causes of Death 2019 ... 27

Appendix C: Mayor's Order 2009-225 ... 29

ACKNOWLEDGMENTS ... 36

EXECUTIVE SUMMARY

The District of Columbia Developmental Disabilities Fatality Review Committee (hereinafter known as the "DDFRC" or the "Committee") is pleased to present its twelfth Annual Report.

The DDFRC was initially established in February 2001, by Mayor's Order 2001-27, and re-established in September 2009 by Mayor's Order 2009-225 as the Developmental Disabilities Fatality Review Committee (see Appendix A). The Committee is charged with examining the events surrounding the deaths of individuals 18 years of age and older who were receiving services from the District of Columbia Department on Disabilities Services (DDS) at the time of death.

KEY FINDINGS FROM DEATHS REVIEWED FROM 2019 (N=33)

During the calendar year 2019, the Committee reviewed 33 fatalities of DDS individuals who died between the years 2018 through 2019. The following is a summary of the data included in the 2019 Annual Report.

- **Of the fatalities reviewed, thirty (91%) were attributed to natural causes.**
- **Nineteen (58%) of the individuals were over the age of 60.**
- **Eight (24%) of the individuals were over the age of 70.**
- **Twenty-nine (88%) were African American.**
- **Average age at death was 59 years.**

DDFRC TRENDS AND RECOMMENDATIONS FROM 2018 CASES REVIEWED

Based on the cases reviewed during calendar year 2019, recommendations were issued to the District Government's Department on Disability Services, which related to improved health care, and more careful service coordination and monitoring of individuals receiving services to address their individual needs. (see ***Section II***: DDFRC Trends and Recommendations).

INTRODUCTION

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

MARGARET MEAD

The 2019 Annual Report is a summary of the work performed by the Developmental Disabilities Fatality Review Committee (DDFRC) during calendar year 2019. 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 above-mentioned 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 multi-disciplinary, 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 the individuals' death-related data in order to identify consistent patterns and trends that assist in increasing knowledge related to risk factors and guiding system changes/enhancements. The fatality review process includes the examination of an independent investigative report of each 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 as well as national standards of care. A wide body of reviews results 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 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 who received services through the Department on Disability Services (DDS).

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

- Psychological evaluation, based on one or more standardized tests that document sub-average general intellectual functioning of an IQ score of 69 or below, 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 2010 through 2019, the number of consumers served ranged from 2,026 to 2,540, while the number of DDS deaths during the same ten-year span ranged from 28 to 38 annually.

Table 1:
District of Columbia DDS Population and Deaths 2009 to 2018

Year	DDS Population	Number of DDS Population Deaths	Percentage
2010	2026	35	1.7%
2011	2187	31	1.4%
2012	2227	37	1.7%
2013	2248	33	1.5%
2014	2284	35	1.5%
2015	2317	34	1.5%
2016	2397	35	1.5%
2017	2452	38	1.5%
2018	2540	28	1.1%
2019	2491	34	1.4%

DEMOGRAPHICS

In 2019, the DDFRC reviewed the deaths of thirty-three (33) adult individuals who were served by the DDS Developmental Disabilities Administration (DDS DDA). Table 2 indicates the total number of cases reviewed by the DDFRC since 2015.

Table 2: Number of Fatalities Reviewed Per Year	
Year of Review	**Number of Fatalities Reviewed**
2015	26
2016	35
2017	39
2018	28
2019	33

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.

Figure 1:
Race of decedents (n=33)

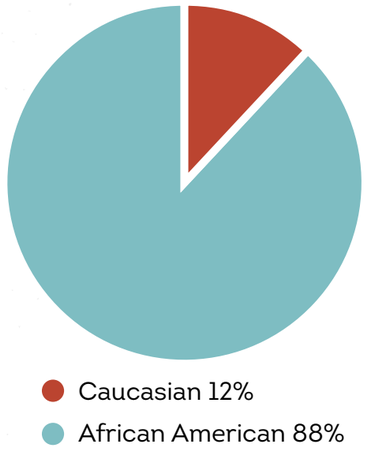
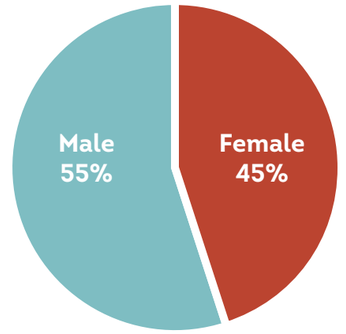


Table 3: Race of Decedents			
Year of Review	**African American**	**Caucasian**	**Other**
2016	26	9	0
2017	30	8	1
2018	19	7	2
2019	29	4	0

Table 3 shows the race of decedents whose cases were reviewed by the DDFRC 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 2:
Race of decedents (n=33)



Gender of Decedents

Of the 33 fatalities reviewed, 18 (55%) DDFRC decedents were male and 15 (45%) were female (Figure 2). As seen in Table 4, a review of the last four years indicates the percentage of decedents who were male ranged from 55% to 74% per year. While there are consistently more deaths among males, the difference between males and females is shrinking.

Table 4: Gender of Decedents		
Year of Review	**Female**	**Male**
2016	13	22
2017	10	29
2018	11	17
2019	15	18

Age of Decedents

Based on the 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 2019, there was only one fatality in which the decedent was under 31 years of age and two who were between the ages of 31 and 40. The average age at death over the last four review periods ranged from 56 - 65.

Figure 3: Effect of Gender on Age of Death (n=33)

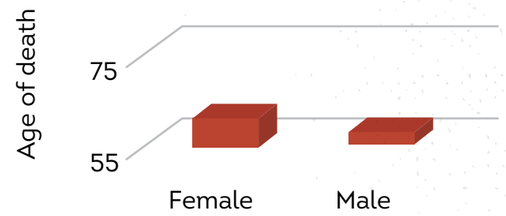


Table 5 depicts the average age at death and age range for each year since 2016. The average age of the decedents at the time of death was 59 years. The CDC (2018) reports that the average age of death for the total US population (with and without disabilities) is 78.7 years. This is 19.7 years longer than the DDFRC sample.

Table 5: Range of Age and Average Age at Death		
Year of Review	Age Range	Average Age
2016	29 - 84	62
2017	20 - 84	56.1
2018	29 - 93	64.8
2019	29 - 83	59

Figure 4: Effect of Race on Age at Death (n=33)

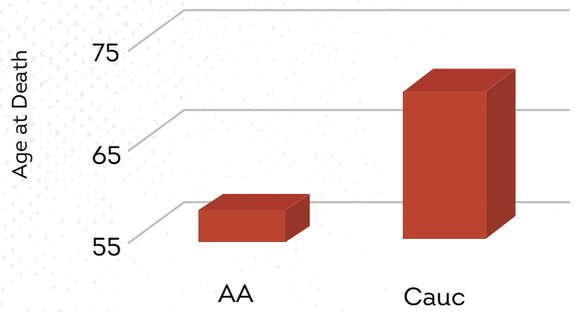
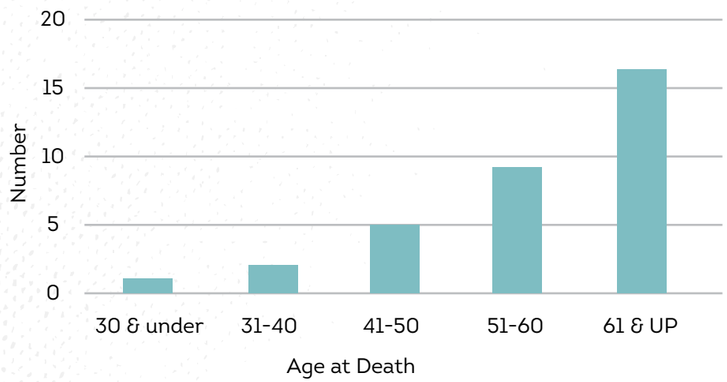


Figure 5: Age of Decedents (n=33)



Effect of Gender and Race of Decedents on Age at Death

The data examined indicated the effect of gender and race, if any, on the age of the decedents. As depicted in Figure 4, there is a small difference between the age of the female decedents (n=18) and the male decedents (n=15.)

Figure 5 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 racial disparity in the DDFRC sample (12.8 years) is much greater than that in the US population overall.

Figure 6: Average Age at Death by Race/Gender

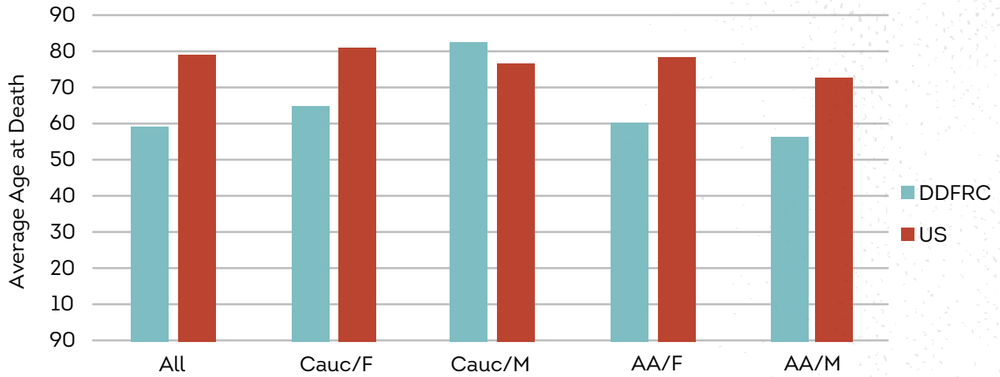


Table 6: Average Age in DDFRC Sample			
	Total	African American	Caucasian
Male	57.6 years (n=18)	56.1 years (n=17)	83 years (n=1)
Female	60.7 years (n=15)	59.8 years (n=12)	64 years (n=3)
Total Sample	59 years (n=33)	57.5 years (n=29)	70.3 years (n=4)

Table 6 shows the average age of decedents by gender and race (N=33) in the 2019 DDFRC review sample.

Type of DDS Residences

The quality of care in various types of residence 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 7, most deaths involved decedents living in Intermediate Care Facility homes (ICF) Supported Living Homes and Nursing facilities.

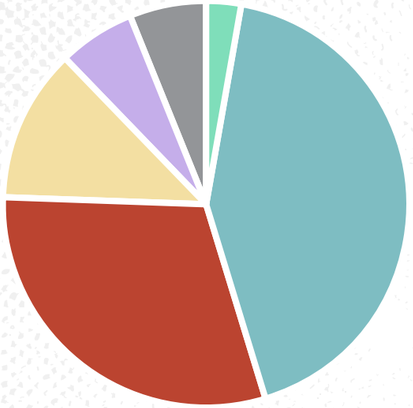


Figure 7: DDFRC Decedent Residence

- Supervised Apt 3%
- ICF 42%
- Supported Living 30%
- Nursing Home 12%
- Natural Home 6%
- Host Home 6%

Location of Fatality

The fatality reviews revealed that the deaths occurred in hospitals, nursing facilities, and residential placements. As depicted in Figure 8, 42% (n=14) of individuals whose cases were reviewed in 2019 died during a hospital admission. 27% died at their place of residence (n=9), and 16% (n=5) were pronounced dead in a hospital emergency department. 3 individuals died in an inpatient hospice (10%) and 2 in a nursing home (6%).

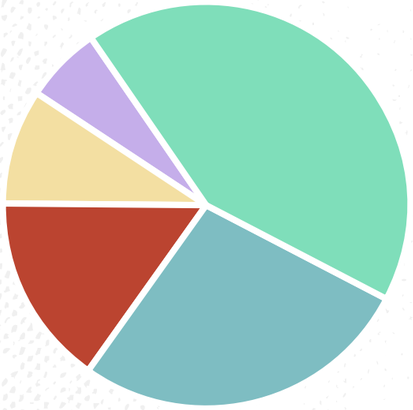


Figure 8: Place of Death

- Hospital 14%
- Home 9%
- Hospital ER 5%
- Inpatient Hospice 3%
- Nursing Home 2%

Mobility and Mealtime Assistance

Mobility and impairments with food intake among individuals with intellectual and developmental disabilities are recognized problems that place individuals at a 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, eight (24%) of individuals were on a regular textured diet, while 13 (39%) 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 12 (36%) individuals.

Table 7: Food Textures

Textures	2016	2017	2018	2019
Regular	14	24	7	8
Pureed/Mechanical Soft	14	4	12	12
G-tube Dependent	17	11	9	13

Table 8 indicates the type of mobility for DDFRC decedents whose cases were reviewed over the past four years. In 2019, 20 (61%) decedents required the use of a wheelchair, and 5 (15%) required support (gait belt, walker, etc.). Eight people (24%) were mobile without support.

Table 8: Individual's Method of Mobility

Method of Mobility	2016	2017	2018	2019
Mobile Without Support	7	12	0	8
Mobility Requiring Support	8	10	12	5
Mobility Requiring Wheelchair Use	20	17	16	20

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. 20 of the 33 DDFRC individuals (61%) had one or more mental health diagnoses. Thirteen (39%) had none.

Table 9: Mental Health Diagnoses of Decedents Reviewed in 2019		
Mental Health Diagnoses	Number of Decedents	Percent of Decedents
0	13	39%
1	10	30%
2	7	21%
3	2	6%
4 or more	1	3%

Figure 9: Mental Health Diagnoses

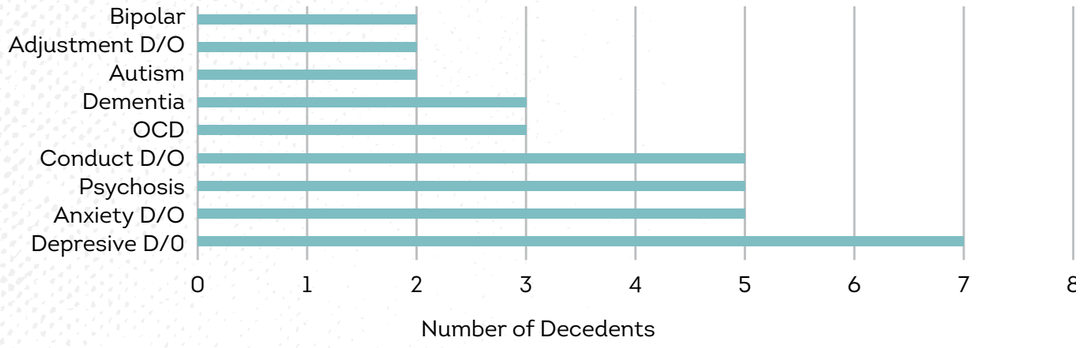


Table 10 describes the individual's level of functioning as related to intellectual disability as provided in the mortality investigative reports reviewed by the DDFRC.

- **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, they 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.

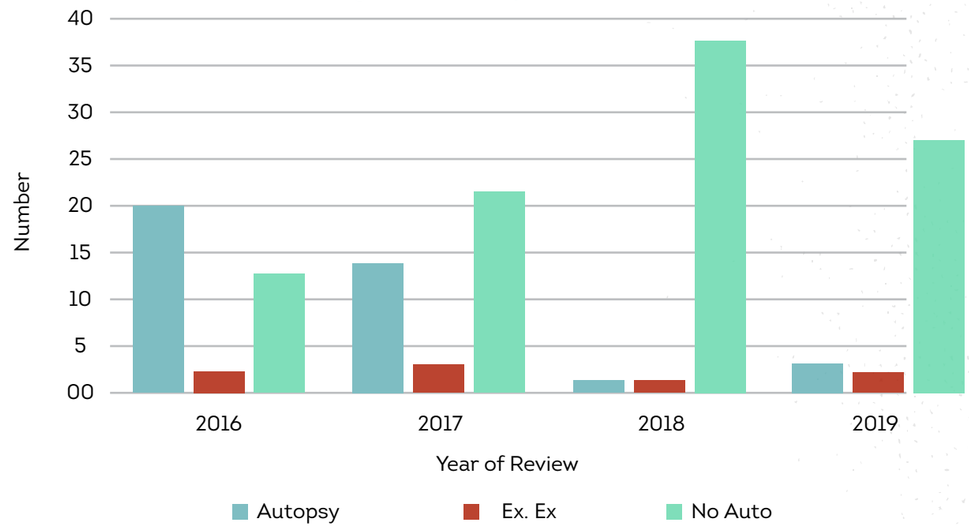
Table 10: DD FRC Individual's Cognitive and Adaptive Level of Functioning		
Level of Functioning	Cognitive	Adaptive
Profound	10	15
Severe	7	7
Moderate	8	4
Mild	7	6
Unknown	1	1

MANNER AND CAUSE OF DEATH

Autopsies

Figure 10 depicts the number of autopsies conducted per year for the past four years. Of the 33 individuals whose cases were reviewed in 2019, 3 autopsies were completed. 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.

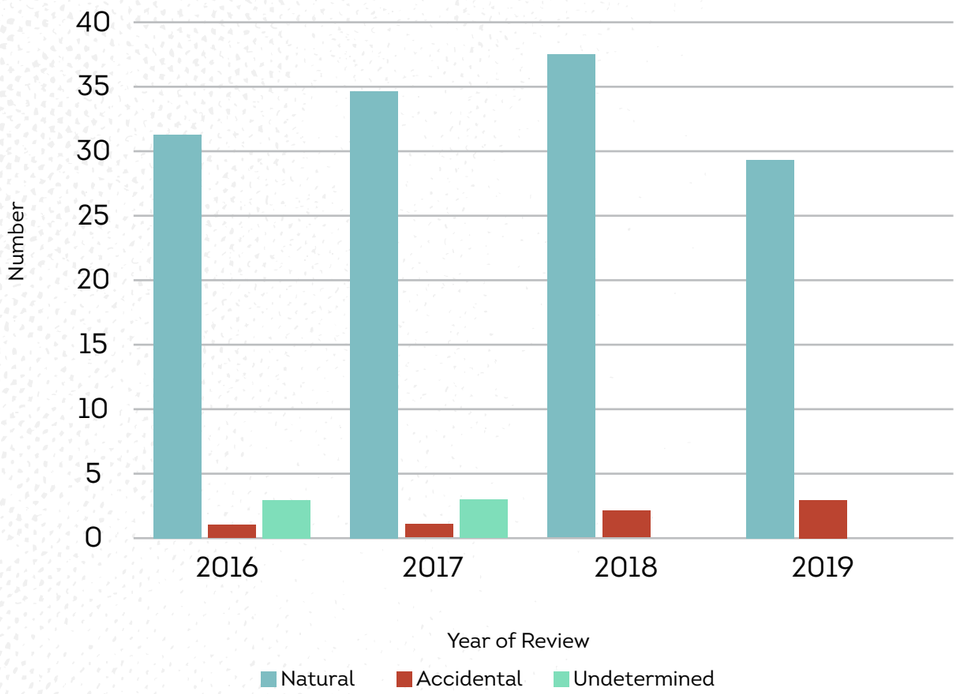
Figure 10: Autopsies Conducted



Manner of Death

Figure 11 depicts the manner of death provided to DDFRC for the past four years. There are five manners of death including homicide, suicide, accidental, 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, 30 of the 33 fatalities of the 2019 DDFRC individuals were determined to be natural deaths. The remaining 3 individuals' deaths were ruled accidental.

Figure 11: Manner of Death



Causes 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 2019. Most of the DDFRC individuals died of Respiratory Disease (36%), followed by Cardiovascular Disease (24%).One individual died of Cardiopulmonary Disease and Gastrointestinal System disorder (6%). Four individuals each died because of Infectious Disease and Cancer (24%). Three (9%) individuals died of trauma.

Table 11: Causes of Death

Cause of Death	2016	2017	2018	2019
Respiratory Disease	8	8	5	12
Cardiovascular System Disorder	11	15	16	8
Infectious Disease	1	3	3	4
Cancer	4	4	1	4
Trauma	1	1	0	3
Gastrointestinal System	2	2	2	1
Cardiopulmonary System Disorder	0	0	0	1
Other	0	0	1	0
Genetic Disorder	2	4	0	0
Unknown	3	0	0	0
Multi-system Organ Failure	1	1	0	0
Diabetes	0	1	0	0
Renal System	1	0	0	0
Sepsis	1	0	0	0

SECTION II:
TRENDS AND RECOMMENDATIONS

> Each mortality review includes the reviewer's recommendations for corrective or preventative action based on the circumstances around the care and death of the specific person.

Over time, the reviewers have identified areas in which recommendations are frequently made. These may include recommendations for action by DDS or by specific provider agencies. The most listed recommendations for the 2019 review period are provided here. The following acronyms are used in this report:

DDA = Developmental Disabilities Administration

DDS = Department on Disabilities Services

HCMP = Health Care Management Plan

MCIS = DDS Consumer Information System

Recommendations Based on Deaths Reviewed in 2019
Health Passports are complete, accurate, and up-to-date and include all medical diagnoses, allergies, vaccination information, etc., as per DDA Health and Wellness Standard 1.
HCMPs are complete, accurate, and up-to-date and include interventions for all individual specific concerns as per DDA Health and Wellness Standard 5.
End-of-life planning is offered and documented for all individuals supported as per DDA Health and Wellness Standard 24.
All physician orders and clinician recommendations are implemented and documented or the rationale for not implementing the order/recommendation is clearly documented as per DDA Health and Wellness Standard 2.
All support staff are adequately trained to recognize a change in an individual's condition, a life-threatening situation, and when to seek prompt medical attention as per BLS and CPR certification standards.
All caregivers should ensure a person's diagnoses are consistently and accurately documented in all of the person's records as per DDA Health and Wellness Standard 2.

During calendar year 2019, the following recommendations were issued to the DDFRC based on the 33 fatalities of individuals with intellectual disabilities as completed by the Committee.

Recommendation #1

The Department on Disability Services shall implement a seizure protocol and provide in-service training to providers for managing seizures.

Agency Response

The Department on Disability Services Health and Wellness nurses will provide technical assistance to the provider community that serve and support individuals with seizure disorders. The technical assistance will include but is not limited to training on signs and symptoms of seizures. The Health and Wellness nurses along with the Service Coordinator will identify persons on their caseload with seizure disorders to ensure proper health services are being rendered.

The Department on Disability Services Service Coordinators will identify all persons on their case load with a seizure disorder. This information will be shared with the Health and Wellness nurse assigned to that provider. The Health and Wellness nurse will develop dialog with providers and offer technical assistance to the provider in the area of training and treatment of individuals they serve with a seizure disorder. The Department on Disability Services has included a section on their monitoring tool which gathers data on unmet needs of the individual. This information will be shared with the Health and Wellness nurse assigned to that provider and will be entered into the MCIS system for follow up. The Health and Wellness nurse will monitor the issues until closed in the system due to the issue being rectified.

Persons being served by The Department on Disability Services with seizure disorders will receive all needed services. Also, the providers serving these individuals will be better trained to provide the services and support needed to the individual. The Department on Disability Services will collect random samples of data from the monitoring tool's unmet needs section and analyze to ensure none of the individual's being served will have unmet needs.

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Recommendation #2

The Department on Disability Services shall review and implement salient recommendations from the National Safety Forums: Safe Practice for Healthcare updates 2010 – specifically Safe Practice #17: Medication Reconciliation and Safe Practice #18: Pharmacy Leadership Structures and Systems.

Agency Response:

The DDS Health and Wellness unit along with Service Coordinators will monitor the updating and accuracy of the Health Management Care Plan to ensure discontinued medications are listed on the Health Management Care Plan in accordance with the Health and Wellness Standards. The Department on Disability Services Health and Wellness nurse assigned to this provider along with Service Coordination will monitor all providers to ensure they are following the DDS Health and Wellness Standards. Safe Practices and Medication Reconciliation are covered in the Health and Wellness Standards under measures 5 and 17.

The Department on Disability Services has developed the Health and Wellness Standards which can be used as a guide for providers on how to render safe practices of healthcare. These Health and Wellness Standards are routinely reviewed by Quality Management for changes and updating of the Standards. All providers rendering services to DDS individuals are required to adhere to the DDS Health and Wellness Standards per DDS policy. Service Coordination monthly monitoring tool will monitor providers for compliance with the DDS Health and Wellness Standards.

Recommendation #3

The Department on Developmental Services Individual Service Plan (ISP) shall ensure that clients receive adequate supervision and monitoring in accordance with the Individual Service Plan or that which is appropriate with the physical safety and care needs of the individuals.

Agency Response

During development of the annual ISP, DDS Service Coordinators will ensure the appropriate supervision and monitoring for an individual is discussed and included in the annual ISP. The proper staff to individual ratio will be included in the ISP as well as what level of supervision is needed according to the individual's needs. DDS Service Coordinators will begin to check the ISP's for everyone on their caseload and check the level of supervision to ensure their individuals have adequate supervision and monitoring according to their individual's support plan.

Service Coordinators will begin to include this information on their monthly monitoring tool which is entered into the MCIS system monthly. Data from the monitoring tool entered monthly into the MCIS System on any individual that does not have adequate supervision and monitoring will be reviewed quarterly by the Quality Improvement Committee to ensure all individuals being served by DDS are adequately supervised and monitored.

Recommendation #4

The Department on Developmental Services shall ensure that Primary Care Physicians obtain a timely review of Dilantin (Phenobarbital) levels and maintain these levels in the therapeutic ranges for the management of seizure in individuals.

Agency Response

DDS will continue to encourage providers to adhere to the Health and Wellness Standards which outline the responsibility of the provider nurse to share all health concerns with the primary care physician.

There are specific guidelines outlined in the Health and Wellness Standards which state how often Dilantin levels are reviewed and what must happen if the levels are not within normal limits. DDS Service Coordinators will collaborate with the Health and Wellness Supervisors when problems or issues are discovered during monthly monitoring. DDS Service Coordinators will also record any issues or problems during their monthly monitoring, which will be included on the monthly monitoring tool that is entered in the MCIS system. Any issues or problems discovered by the Service Coordinator will be put into the Alert Resolution System for monitoring and follow up. DDS Service Coordinators will check their caseloads for individuals diagnosed with seizure disorder. Once the seizure disorder is identified, the Service Coordinator ensures the provider nurse follows the Health and Wellness Standards which states the primary physician should review all lab work to ensure it is within normal limits. It also gives the primary care physician an opportunity to treat any problems noted in the lab report in a timely manner.

Recommendation #5

The Department on Disability Services shall implement measures to ensure that durable medical equipment is maintained in a safe and functioning manner. Resources include the Center for Medicare and Medicaid rules/ website and provider tools for quality standards that providers must meet.

Agency Response

DDS Service Coordinators along with the Provider Resource Management Unit will monitor providers monthly to ensure all medical equipment is in good working condition. DDS Service Coordinators along with the Provider Resource Management Unit began reviewing all adaptive equipment used by individuals served to ensure it is in good working condition in September 2011. The Provider Resource Management will work with the providers to ensure that the tools being used by provider agencies are in appropriate working conditions and that the adaptive equipment meets Medicare and Medicaid approval.

The Service Coordinators will complete monthly reviews of all the individuals on their case load to ensure all adaptive equipment is working properly. As of June 2012, the Provider Resource Management Unit began working with providers on developing a Medicaid approved measurement tool to ensure the equipment is working properly.

Recommendation #6

The Department on Disability Services should develop and disseminate a policy related to the emergency transport of consumers.

Agency Response

All providers supporting individuals eligible for DDS/ DDA services will have an emergency transport policy to ensure individuals in need of transport are transported using proper services. DDS Quality Improvement Specialist along with staff from Provider Resources will conduct an audit of all providers to ensure providers have a policy on emergency transport for individuals in need. DDS Mortality Review Coordinators received a copy of the District of Columbia's Emergency Transport Policy which has been uploaded to the DDS website for review by all providers. Provider's supporting services individuals eligible for DDS/DDA services will have an emergency transport policy as part of their standard policy and procedures.

Individuals being served by DDS in need of emergency transport to medical facilities will be transported according to the providers' emergency transportation policy. The results of this policy will decrease the number of providers transporting individual in company vans to medical facilities.

APPENDICES

Appendix A

Glossary of Terms

TERMS	DEFINITIONS
Autopsy Report	A detailed report consisting of the autopsy procedure, microscopic and laboratory findings, a list of diagnoses, and a summary of the case
CRF/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 fewer individuals (also includes foster care)

Supervised Apartments Typically, a living arrangement for one to three customers with mental retardation, with drop-in twenty-four-hour supervision. Supervised Apartments may be single units grouped in a cluster within an apartment complex, or scattered throughout a complex.

Appendix B

Causes Of Death - 2019
DD FRC Deaths Reviewed

Deaths Reviewed that Occurred in 2018				
Age	Race	Sex	Cause of Death	Manner of Death
64	C	F	Hemorrhagic stroke and atherosclerotic vascular disease	Natural
62	AA	M	Pneumonia	Natural
59	AA	F	Pulmonary embolism, cerebrovascular accident and hypertension	Natural
55	AA	F	Abdominal injuries (car accident)	Accidental
37	AA	M	Brain malignant neoplasm	Natural
59	AA	M	Atherosclerotic cardiovascular disease	Natural
62	C	F	Complications of gastric perforation due to nasogastric tube placement	Accidental
62	AA	M	Respiratory failure	Natural
29	AA	M	Aspiration pneumonia and CP	Natural
60	AA	M	Cardiac arrest and cardiomyopathy	Natural
66	C	F	Metastatic Breast Cancer	Natural
46	AA	M	Sepsis due to Staphylococcus epidermidis	Natural
41	AA	M	Encephalopathy and urosepsis	Natural
66	AA	F	Complications of left middle cerebral artery infarct	Natural
82	AA	M	Acute hypoxic respiratory failure due to pneumonia	Natural
41	AA	M	Sepsis, and community acquired pneumonia	Natural
76	AA	M	Cardiac arrest, acute blood loss anemia, GI bleeding, or unknown etiology	Natural

Deaths Reviewed that Occurred in 2019				
Age	Race	Sex	Cause of Death	Manner of Death
47	AA	F	Asphyxia due to choking	Natural
71	AA	F	Hypoxia	Natural
60	AA	F	Alzheimer's Disease and Down Syndrome	Natural
62	AA	F	Colon Cancer	Natural
74	AA	M	Cardiorespiratory arrest due to Parkinson's disease	Natural
41	AA	M	Diabetic ketoacidosis	Natural
77	AA	M	Atonic colon/Ogilvie's syndrome	Natural
83	C	M	Pneumonia	Natural
36	AA	F	Complications of Friederichs's Ataxia	Natural
72	AA	F	Pneumonia	Natural
60	AA	F	Atelectasis of right lung, bronchial bleeding, and lung cancer	Natural
76	AA	F	CHF and pulmonary fibrosis	Natural
63	AA	M	Acute respiratory failure due to pneumonia	Natural
51	AA	M	Respiratory failure due to complications of CP	Natural
53	AA	M	Cerebral palsy	Natural
54	AA	F	Complications of cerebral palsy	Natural

Appendix C

GOVERNMENT OF THE DISTRICT OF COLUMBIA

ADMINISTRATIVE ISSUANCE SYSTEM

Mayor's Order 2009-225
December 22, 2009

SUBJECT: Revitalization –District of Columbia Developmental Disabilities Fatality Review Committee

ORIGINATING AGENCY: Office of the Mayor

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

I. ESTABLISHMENT

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

II. PURPOSE

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

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

III. DUTIES

The duties of the Committee shall include:

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

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

C. Reviewing and evaluating services provided by public and private systems that are responsible for protecting or providing services to District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability, and assessing whether said entities have properly carried out their respective duties and responsibilities; and

D. Based on the results of the reviews (both individual and in the aggregate), identifying strengths and weaknesses in the governmental and private agencies and/or programs that serve District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability and making recommendations to the Mayor and the agencies and programs directly to implement systemic changes to improve services or to rectify deficiencies. The recommendations may address, but are not limited to, proposing statutes, policies or procedures (both new or amendments to existing ones); modifying training for persons who provide services to District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability; enhancing coordination and communication among entities providing or monitoring services for District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability; and facilitating investigations of fatalities, providers of service or individual medical and allied health practitioners.

IV. FUNCTIONS

The functions of the Committee shall include:

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

1. Methods by which deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability are identified and reported to ensure expeditious reviews;

2. A process by which fatality cases are screened and selected for review;

3. A method for ensuring that all information identifying District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability, their families and others associated with the cases or the circumstances surrounding the deaths, including witnesses and complainants, is protected against undue disclosure. This is to ensure that steps are taken to protect the right to privacy of an individual and his or her family in conducting investigations. Disseminating information to Committee members, reporting as required by the Mayor's Order, and maintaining case records for the Committee;

4. A method for gathering individual and cumulative data from the reviews;

5. A method for reviewing whether recommendations generated by the Committee are being implemented and identifying problems related to obstacles/barriers to implementation; and

6. A method for evaluating the work of the Committee that takes into account community responses to the deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability.

B. On or about December 30th of each year, beginning in 2010, producing an annual report that provides information obtained from the reviews of deaths that occurred during the previous calendar year. The annual report shall be submitted to the Mayor and made available to the public. The information to be contained in the report shall include at a minimum:

1. Statistical data on all fatalities of District residents over the age of 18 with an intellectual disability and/or a qualifying developmental disability reviewed by the Committee, including numbers reviewed, demographic characteristics of the subjects, and causes and manners of deaths;

2. Analyses of the data generated by the reviews to demonstrate the types of cases reviewed (which may include illustrative case vignettes without identifying information), similarities or patterns of factors causing or contributing to the deaths and trends (including temporal and geographic); and

3. Recommendations generated from the reviews, including service enhancements, systemic improvements or reforms, and changes in laws, policies, procedures or practices that would better protect District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability and that could prevent future deaths.

V. COMPOSITION

A. Members shall be appointed by the Mayor based on individual expertise in relevant disciplines and their familiarity with the laws, standards and services related to the protection of the health and welfare of individuals with an intellectual disability or a developmental disability. As such, the composition of the Committee shall reflect medical and clinical professionals from various disciplines who serve consumers with an intellectual disability or developmental disabilities, and persons representing the advocacy community. All newly appointed Committee members shall be District residents.

B. The Committee membership shall consist of:

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

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

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

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

VI. TERMS

A. Public members appointed to the Committee shall serve for three (3) year terms, except that of the members first appointed, one-half shall be appointed for three (3) year terms and one-half for two (2) year terms. The date on which the first members are installed shall become the anniversary date for all subsequent appointments.

B. Members appointed to represent District government agencies shall serve only while employed in their official positions and shall serve at the pleasure of the Mayor.

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

D. A member appointed to fill an unexpired term shall serve for the remainder of that term.

E. A member may hold over after the member's term expires until reappointed or replaced.

F. A public member may be excused from a meeting for an emergency reason. A public member who fails to attend three (3) consecutive meetings shall be deemed to be removed from the Committee and a vacancy created. Such vacancies shall be filled by the Mayor, in accordance to the composition outlined in Section V of this Mayor's Order.

G. A public member may be removed by the Mayor for personal misconduct, neglect of duty, conflict of interest violations, incompetence, or official misconduct. Prior to removal, the public member shall be given a copy of any charges and an opportunity to respond within ten (10) business days following receipt of the charges. Upon a review of the charges and the response, the Director of the Office of Boards and Commissions, Executive Office of the Mayor, shall refer the matter to the Mayor with a recommendation for a final decision or disposition. A public member shall be suspended by the Director of the Office of Boards and Commissions, Executive Office of the Mayor, on behalf of the Mayor, from participating in official matters of the Committee pending the consideration of the charges.

VII. ORGANIZATION

A. The Mayor shall appoint the Chief Medical Examiner and the DDS Deputy Director for the Developmental Disabilities Administration, or the functional equivalent, as Co-Chairpersons of the Committee and they shall serve in these capacities at the pleasure of the Mayor.

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

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

VIII. FULL COMMITTEE

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

B. Meetings of the full Committee shall be held for the purposes of:

1. Conducting case reviews or assessing additional data from prior cases that have since become available;
2. Considering recommendations arising from available case reviews;
3. Preparing an annual report; and
4. Conducting any other business necessary for the Committee to operate or fulfill its duties.

C. Case review meetings of the full Committee shall be held monthly, if there are cases for review. After procedures have been established and tested, the Committee may consider holding case review meetings every other month (bi-monthly), if practicable. The full Committee may also convene additional meetings as needed for additional case reviews, or for other specific purposes of the Committee, including the development of recommendations or preparation of the annual report.

IX. SUBPOENA POWER

A. When necessary for the discharge of its duties, the Committee shall have the authority to issue subpoenas to compel witnesses to appear and testify and to produce books, papers, correspondence, memoranda, documents, or other relevant records. The Mayor hereby delegates the said authority to the Committee, to the extent necessary and appropriate to effectuate the Committee's duties, pursuant to section 3 (a) of the Independent Personnel Systems Implementation Act of 1980, effective September 26, 1980, D.C. Law 3-109, D.C. Official Code § 1-301.21(a) (2006 Repl.).

B. Except as provided in paragraph 3 of this section, subpoenas shall be served personally upon the witness or his or her designated agent, not less than five (5) business days before the date the witness must appear or the documents must be produced by one of the following methods, which may be attempted concurrently or successively:

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

X. CASE REVIEW CRITERIA AND PROCEURES

A. Case Review Criteria
The Committee shall review the following deaths:

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

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

b. Abuse, either physical or sexual;

c. Neglect, including medical and custodial;

d. Malnourishment or dehydration; and

e. Circumstances or events deemed suspicious.

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

ACKNOWLEDGMENTS

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

The willingness of Committee members to step outside of their traditional professional roles to examine the circumstances that may have contributed to these deaths and to seriously consider ways to improve the quality of life and prevent future fatalities is an admirable and difficult challenge. This challenge speaks to the commitment of members to our goal of improving services and making life better for the residents of this city. Without this level of dedication, the work of the Committee would not be possible.

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

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

401 E Street, SW, Washington, DC 20024
202.698.9000
https://ocme.dc.gov/
ocme@dc.gov

DC DEPARTMENT OF DISABILITY SERVICES

250 E Street, SW, Washington, DC 20024
Phone: 202.730.1700
Email: dds@dc.gov