

DISTRICT OF COLUMBIA **DEVELOPMENTAL DISABILITIES FATALITY REVIEW COMMITTEE**



2018 Annual Report

2018 ANNUAL REPORT

District of Columbia Developmental Disabilities Fatality Review Committee

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
Citizens of the District of Columbia

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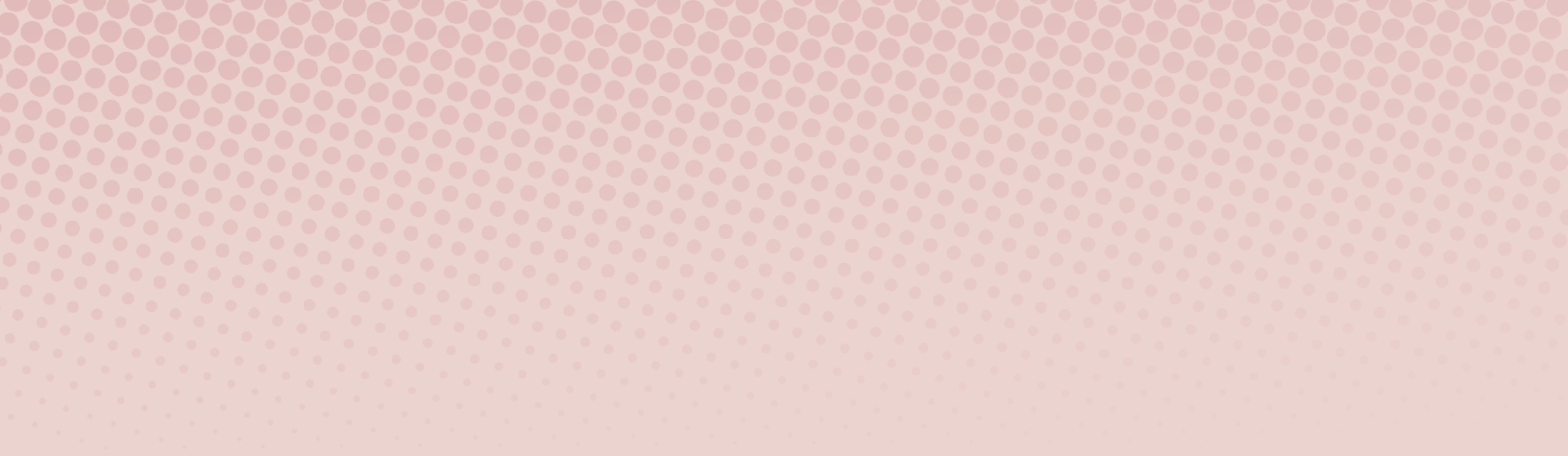
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EXECUTIVE SUMMARY

The District of Columbia Developmental Disabilities Fatality Review 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 of 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 2018 (N=28)

During the calendar year 2018, the Committee reviewed 28 fatalities of DDS individuals who died between years 2017 through 2018. The following is a summary of the data included in the 2018 Annual Report.

- Of the 28 fatalities reviewed, 100% were attributed to natural causes.
- Nineteen (67.9%) of the individuals were over the age of 60.
- Eight (28.6%) of the individuals were over the age of 70.
- Nineteen (67.9%) of the individuals were African American.
- Average age at death was 64.8 years.

DDFRC TRENDS AND RECOMMENDATIONS FROM 2018 CASES REVIEWED

Based on the cases reviewed during calendar years 2018, recommendations were issued to the District Government's Department on Disability Services related to improved health care, service coordination and service monitoring of individuals receiving services to address their individual needs. (see Section III: DDFRC 2013 - 2017 Trends).



“

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



INTRODUCTION

The 2018 Annual Report is a summary of the work performed by the Developmental Disabilities Fatality Review Committee during calendar year 2018. 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 28 fatalities reviewed during the aforementioned year.

The was revitalized 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 and mental health providers, 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 individual's death-related data in order to identify consistent patterns and trends that assist in increasing knowledge related to risk factors and guiding system change/enhancements. The fatality review process includes the examination of an independent investigative report of each 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 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 received services through the Department on Disability Services (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.

DDFRC TRENDS AND RECOMMENDATIONS FROM 2018 CASES REVIEWED

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 2009 through 2018, the number of consumers served ranged from 1,946 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 fairly consistent.

TABLE 1: DISTRICT OF COLUMBIA DDS POPULATION AND DEATHS 2009 TO 2018

Year	DDS Population	Number of DDS Population Deaths	Percentage
2009	1946	29	1.5%
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%

In 2018, the DDFRC reviewed the deaths of twenty-eight (28) 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

DDFRC TRENDS AND RECOMMENDATIONS FROM 2018 CASES REVIEWED

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=19, 68%). As seen in Figure 1, seven (25%) were Caucasian and the remaining two (7%) were “Other” (Asian and Hispanic).

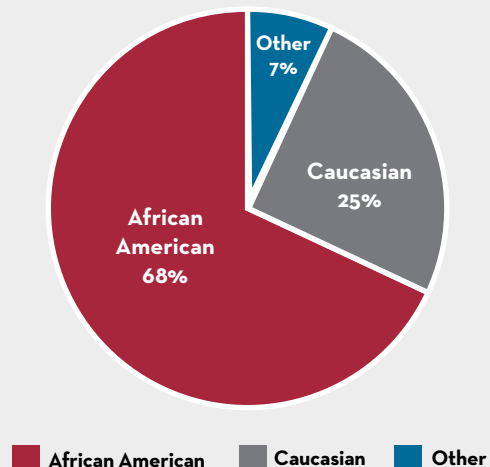
Figure 1: Race of Decedents (n=28)

Table 3 shows the number of decedents of each race over the last four years.

TABLE 3: RACE			
Year of Review	African American	Caucasian	Other
2015	22	4	0
2016	26	9	0
2017	30	8	1
2018	19	7	2

Gender of Decedents

Of the 28 fatalities reviewed, 17 (61%) DDFRC decedents were male and 11 (39%) were female (Figure 2). As seen in Table 4, a review of the last 4 years indicates the percentage of decedents who were male ranged from 58% – 74% per year.

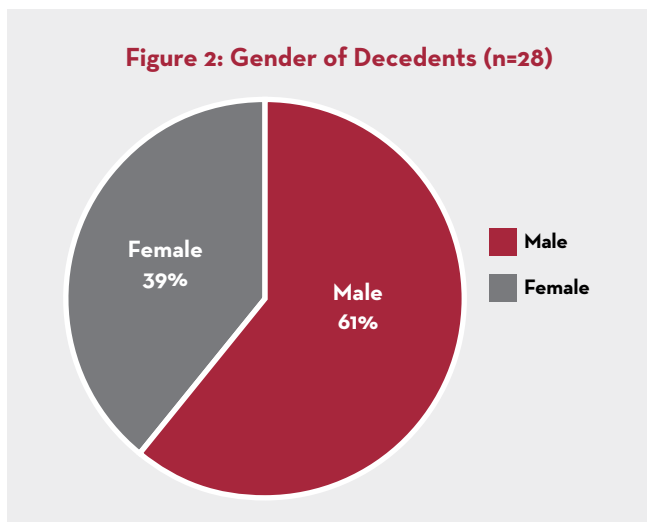


TABLE 4: GENDER		
Year of Review	Female	Male
2015	11	15
2016	13	22
2017	10	29
2018	11	17

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, the majority of decedents were over the age of 61. During 2018, there was only one fatality in which the decedent was under 31 years of age and one who was between the ages of 31 and 40. The average age at death over the last 4 review periods ranged from 56 – 64.8.

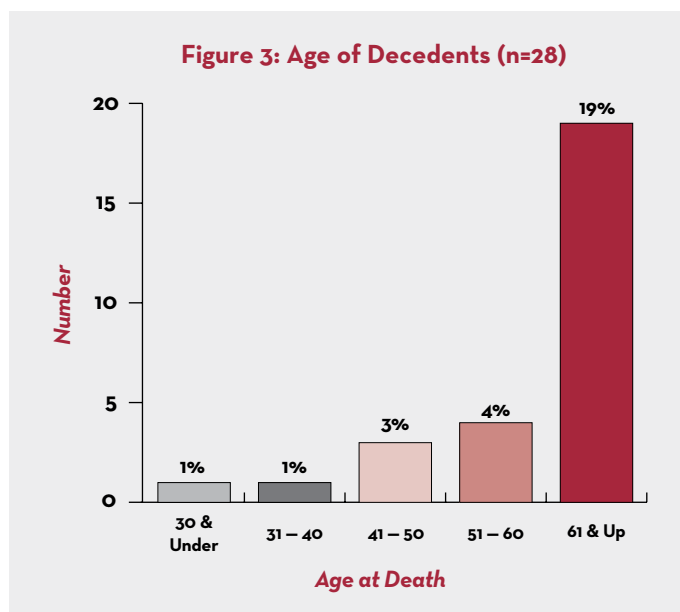


Table 5 depicts the average age at death and age range for each since 2015. The average age of the decedents at the time of death was 64.8 years. The CDC (2017) reports that the average age of death for the total US population (with and without disabilities) is 78.6 years. This is 13.8 years more than the DDFRC sample.

TABLE 5: RANGE OF AGE AND AVERAGE AGE AT DEATH		
Year of Review	Age Range	Average Age
2015	23 - 89	56
2016	29 - 84	62
2017	20 - 84	56.1
2018	29 - 93	64.8

Effect of Gender and Race of Decedents on Age at Death

The data was examined to determine the effect of gender and race, if any, on the age of the decedents. As depicted in Figure 4, there is little difference between the age of the female decedents (n=11) and the male decedents (n=17). Figure 5 shows that, although gender had little effect, the race of the decedents was a factor in the age at death. Caucasian decedents (n=7) had the longest average lifespan, while African-Americans (n=19) had the shortest. Although this is consistent with the overall statistics for the US (CDC, 2017), the disparity between the DDFRC sample (18.7 years) is much greater than in the US population overall (3.75).

Figure 4: Effect of Gender on Age at Death



Figure 5: Effect of Race on Age at Death

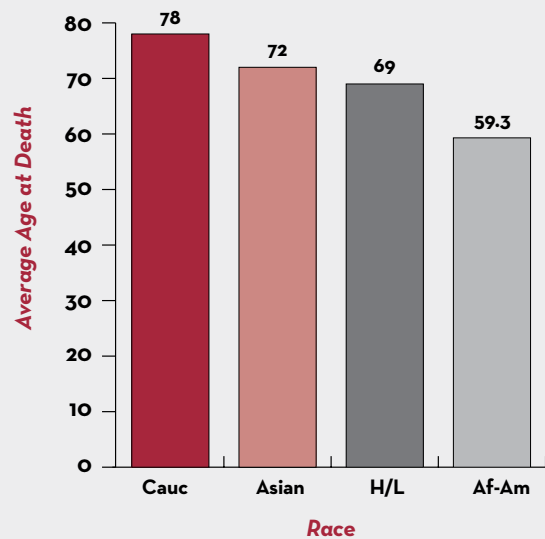


Figure 6 depicts the age at death of the decedents based on race/gender combinations. There does not appear to be an interaction between race and gender as females had a longer lifespan than males regardless of race. Caucasians had a longer lifespan than African -Americans regardless of gender.

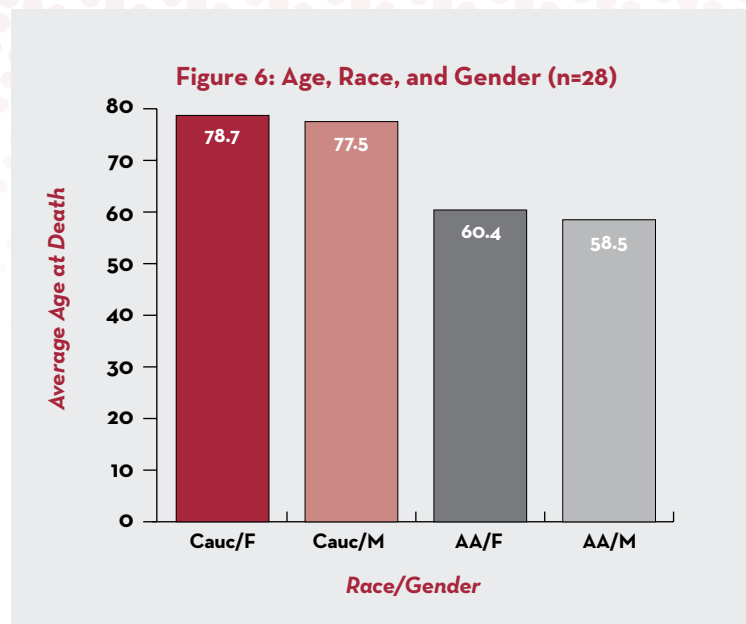
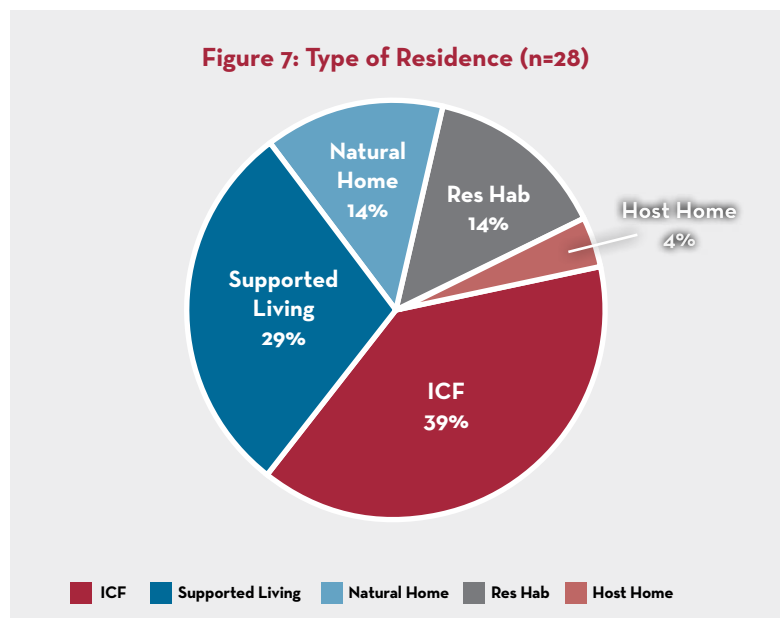


Table 6 shows the average age of decedents by gender and race (N=28) in 2018 DDFRC review sample.

TABLE 6: AVERAGE AGE IN DDFRC SAMPLE					
	Total	African American	Caucasian	Asian	Hispanic/Latino
Males	64.4years (n=17)	58.5 years (n=11)	77.5 years (n=4)	69.0 years (n=1)	72.0 years (n=1)
Females	65.4 years (n=11)	60.4 years (n=8)	78.7 years (n=3)	n/a	n/a
Total Sample	64.8 years (n=28)	59.3 years (n=19)	78.0 years (n=7)	69.0 years (n=1)	72.0 years (n=1)

Type of DDS Residence

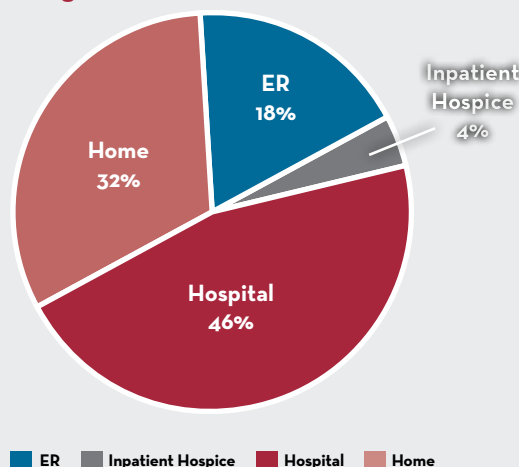
Quality of care in various types of residences can be measured in many ways, one of which is by looking at mortality rates for each residential type. The 28 fatalities reviewed involved individuals who resided in their natural homes or community based placements where their specialized needs could be met. As shown in Figure 7, the majority of deaths involved decedents living in an Intermediate-Care Facility (ICF) home (39.3%) or a Supported Living home (28.6%). The final decedent (3.6%) was noted to have lived in a Host Home.



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 8, of the 28 decedents, the majority of individuals (46.4%) died during a hospital admission, or at their place of residence (32.1%), and 5 (17.9%) were pronounced dead in a hospital emergency room, and one died in inpatient hospice (3.6%).

Figure 8: Place of Death (n=28)



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 28 fatalities reviewed, 7 (25%) of individuals were on a regular textured diet while 9 (32.1%) required the use of a Gastronomy tube for the majority 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 12 (42.9%) individuals.

In Table 8, the data show the type of mobility for DDFRC decedents over that past four years. In 2018, 16 (57.1%) decedents required the use of a wheelchair, and 12 (42.9%) required support (gait belt, walker, etc.). An interesting finding was that no decedent reviewed during this period was mobile without support. This was not the case over the last several years.

Table 7: Food Textures

Textures	2015	2016	2017	2018
Regular	9	14	24	7
Pureed/ Mechanical Soft	8	14	4	12
G-tube Dependent	9	17	11	9

Table 8: Individual’s Method of Mobility

Method of Mobility	2015	2016	2017	2018
Mobile without Support	5	7	12	0
Mobility Requiring Support	9	8	10	12
Mobility Requiring Wheelchair Use	12	20	17	16

Mental Health Diagnoses

The mortality investigative report provides information regarding the diagnosis of individuals with mental health diagnoses as well as the individual's cognitive and adaptive level of functioning. Twelve of the 28 DDFRC individuals (42.9%) had one or more mental health diagnoses, whereas 57.1% (16) had none. One-quarter of the decedents (25%) had two or more mental health diagnoses.

Mental Health Diagnoses	Number of Decedents	Percent of Decedents
0	16	57.1%
1	5	17.9%
2	3	10.7%
3	3	10.7%
4 or more	1	3.6%

Mental Health diagnoses ranged from Autism to Psychosis. For the purpose of this report, diagnoses were categorized by type. For example, generalized anxiety disorder, social anxiety disorder, and panic disorder were categorized as simply "Anxiety". Figure 9 depicts the number of decedents with diagnoses in each category. Of the 12 decedents who had at least one mental health diagnosis, the most common diagnosis category was Psychosis. Seven of the 12 decedents who had at least one diagnosis had a diagnosis of Psychosis. Overall, this number (7) represents 25% of the 28 decedents reviewed by the DDFRC in 2018. The second most common diagnosis category was Conduct Disorder with 5 decedents or 17.9%.

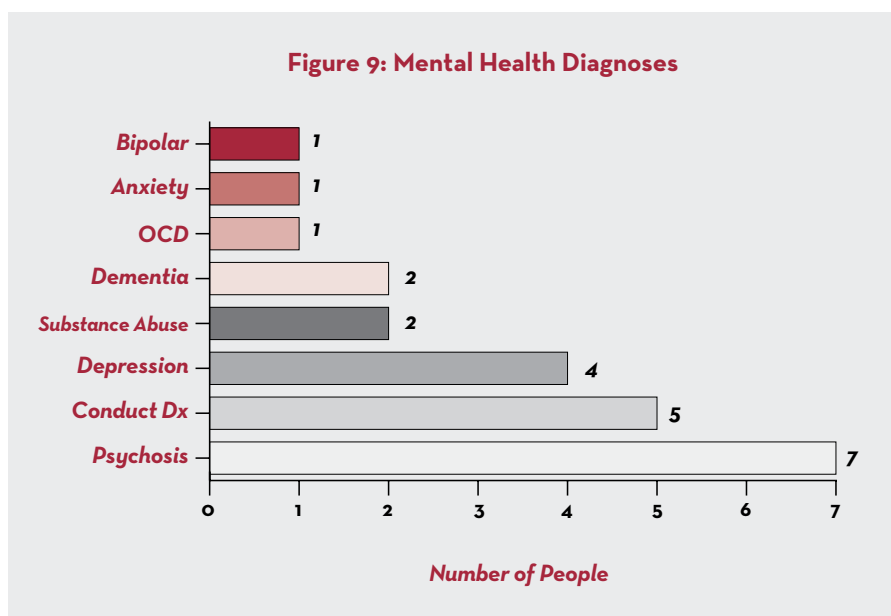


Table 10 provides the individual's level of functioning as related to intellectual disability as provided in the mortality investigative report.

- **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.

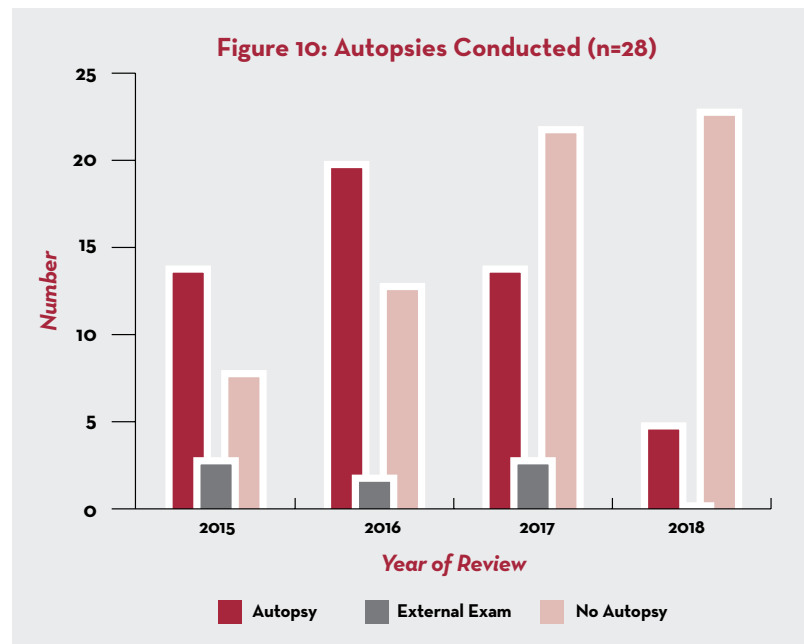
TABLE 10: DDS FRC INDIVIDUAL'S COGNITIVE AND ADAPTIVE LEVEL OF FUNCTIONING(N=28) IN 2018

Level of Functioning	Cognitive	Adaptive
Profound	6	8
Severe	8	4
Moderate	2	3
Mild	9	4
Borderline	1	1
Unknown	2	8

MANNER AND CAUSE OF DEATH

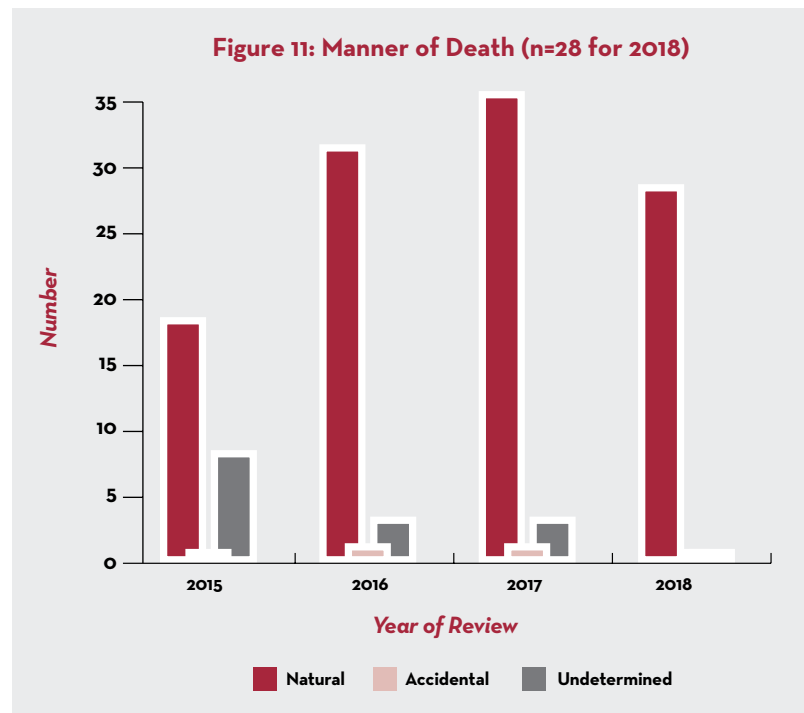
Autopsies

Figure 10 depicts the number of autopsies conducted per year for the past four years. Of the 28 deaths reviewed in 2018, 5 (17.9%) had an autopsy completed. Twenty-three (82.1%) decedents did not have an autopsy or external exam.



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, 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, 100% of the 28 fatalities of the 2018 DDFRC individuals were determined to be natural deaths.



Cause of Death

Table 11 provides a list of the causes of death spanning the past four years and those associated with the 28 fatalities reviewed in 2018. The majority of the DDFRC individuals died as a result of cardiovascular disease (57.1%), followed by Respiratory Disease (17.9%). Three (10.7%) individuals died as a result of an infectious disease, two (7.1%) of gastrointestinal disorders, and one (3.6%) of cancer. No significant trends, either increasing or decreasing, were noted in the frequency of death due to a given cause.

Table 11: Causes of Death				
Cause of Death	2015	2016	2017	2018
Cardiovascular System Disorder	10	11	15	16
Respiratory Disease	10	8	8	5
Infectious Disease	0	1	3	3
Gastrointestinal System	1	2	2	2
Cancer	2	4	4	1
Other	0	0	0	1
Genetic Disorder	0	2	4	0
Unknown	1	3	0	0
Multi-system Organ Failure	1	1	1	0
Asphyxia	0	0	1	0
Diabetes	0	0	1	0
Blunt Impact	0	1	0	0
Renal System	0	1	0	0
Sepsis	1	1	0	0

SECTION II: TRENDS AND RECOMMENDATIONS

DDA

Developmental Disabilities
Administration

DDS

Department on Disabilities
Services

HCMP

Health Care Management Plan

MCIS

MRDDA (now DDS) Consumer
Information System



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 reviewer's have identified areas in which recommendations are frequently made. These may include recommendations for action by DDS or by specific provider agencies. The most commonly listed recommendations for the 2018 review period are listed below. The following acronyms are used in this report:

During calendar year 2018, the following recommendations were issued to DDS based on the 28 fatalities of individuals with intellectual disabilities reviewed 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.

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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.**

Recommendations Based on Deaths Reviewed in 2018

The credentials of the person should be included in all support staff notes as per generally accepted practice.

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.

Medication orders include dose, frequency and indication for use as per DDA Health and Wellness Standard 18.

End-of-life planning is completed 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 generally accepted practice;

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 generally accepted practice.

Ensure all protocols, plans, procedures, etc. are reviewed and updated at least on an annual basis as per generally accepted practice.

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 limit to training on signs and symptoms of seizures. The Health and Wellness nurses along with the Service Coordinator will identify persons on their case load 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.

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.



All providers supporting individuals eligible for DDS/DDA services will have an emergency transport policy

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 Primary Care Physicians timely obtain a review (Phenobarbital) Dilantin 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 Director 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 the tools being used by provider agencies are in appropriate working conditions and that the adaptive equipment meets Medicare and Medicaid approval.

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 tool

that is Medicaid approved. This tool measures 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

<i>Terms</i>	<i>Definitions</i>
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/IDD	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 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 - 2018 DDFRC DEATHS REVIEWED

Deaths Reviewed that Occurred in 2017				
Age	Race	Sex	Cause of Death	Manner of Death
55	AA	F	Acute respiratory distress syndrome	Natural
48	AA	M	Hypotensive cardiovascular disease	Natural
77	C	F	Cardiopulmonary arrest and Bladder Cancer	Natural
61	AA	M	Right sided lobar pneumonia	Natural
68	AA	M	Hypertensive and arteriosclerotic cardiovascular disease	Natural
93	C	F	Hypertensive and arteriosclerotic cardiovascular disease	Natural
69	AA	F	Alzheimer's Disease and Down Syndrome	Natural
51	AA	M	Hypertensive, atherosclerotic, and valvular cardiovascular disease	Natural
62	AA	F	Aspiration pneumonia due to complications of human immunodeficiency virus encephalopathy	Natural
29	AA	F	Mesenteric ischemia	Natural
87	AA	M	Heart Disease	Natural
44	AA	M	Severe aortic regurgitation & dilated cardiomyopathy	Natural
71	AA	F	Complications of choledocholithiasis	Natural
66	C	F	Respiratory failure due to COPD and Interstitial lung disease	Natural
68	C	M	CHF due to dilated cardiomyopathy with regurgitant pulmonary and aortic valves	Natural
89	C	M	CHF in setting of hypertensive atherosclerotic cardiovascular disease	Natural
49	AA	F	Cardiopulmonary arrest, acute respiratory failure, sepsis, aspiration, seizure disorder	Natural
63	C	M	Complications of sepsis due to gastroenteritis	Natural
59	AA	M	Cardiac arrest, GI bleed, gastric and small bowel ischemic ulcer	Natural
64	AA	F	Metastatic lung cancer	Natural
67	AA	M	Hypertensive cardiovascular disease	Natural
54	AA	M	Cardiac arrest, sepsis, seizure	Natural

Deaths Reviewed that Occurred in 2018				
Age	Race	Sex	Cause of Death	Manner of Death
35	AA	M	Atherosclerotic cardiovascular disease	Natural
69	H/L	M	Acute hypoxemia hypercercbic respiratory failure, bilateral pneumonia and respiratory synchytial virus	Natural
72	Asian	M	Septic shock due to pneumonia	Natural
66	AA	M	Multi-organ failure and sepsis	Natural
84	AA	F	Cardiac arrest and health care associated pneumonia	Natural
90	C	M	Arteriosclerotic cardiovascular Disease	Natural





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

VII. ORGANIZATION

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

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

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

VIII. FULL COMMITTEE

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

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

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

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

IX. SUBPOENA POWER

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

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

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

X. CASE REVIEW CRITERIA AND PROCEURES

A. Case Review Criteria

The Committee shall review the following deaths:

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

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

3. The deaths of District residents over the age of 18 years with an intellectual disability and/or a qualifying developmental disability who live in facilities, homes or other living arrangements outside of the District, or who die outside of the District, will be subject to review by the Committee, and will be included in the annual report, both for statistical analysis and recommendations. The Coordinating Staff shall serve as a liaison to his or her counterparts in foreign jurisdictions for the purpose of gathering information and obtaining documents (e.g., police or autopsy reports) to complete the review.

B. Case Review Procedures

1. Case review meetings shall be multi-disciplinary and shall occur within three months of receiving the mortality/fatality report or other sufficient materials required to examine the events and circumstances surrounding the death and to fulfill the purposes and duties of the Committee as enumerated in Sections II and III of this Order. The review may be preliminary, pending conclusion of the investigation and prosecution or release by the prosecutor to conduct the review, at which time a comprehensive review shall be conducted.
2. The case review process shall include presentation of the mortality investigative report, and may include presentations of relevant information concerning the death by any agencies or persons involved with the decedent or that are investigating the event.
3. Following presentation of the facts, the Committee will discuss the case and any issues highlighted, guided by the following principles and questions:
 - a. What factors or circumstances caused or contributed to the death? (This may include consideration of social service delivery and coordination to the decedent and his/her family and compliance with, or development of, applicable or needed laws, procedures and regulations.)
 - b. What responses and investigations resulted from the death? (This includes whether all necessary agencies were notified and responded, and whether any corrective actions were instituted.)
 - c. Were the services, interventions and investigations concerning the decedent appropriate and adequate for his/her needs? (In other words, did the systems, agencies and health care community provide and plan effectively?)
 - d. Were the staff involved with the decedent adequately prepared, trained, and supported to perform their duties correctly?
 - e. Was there adequate communication and coordination among the various entities involved with the decedent? Are the applicable statutes, regulations, policies and procedures adequate to serve the needs of the target population? If not, what changes are needed?

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

XI. CASE NOTIFICATION PROCEDURES

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

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

- B. Case notification reports should include:

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

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

XII. NOTIFICATION OF PARTICIPANTS

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

the review meeting. Any agreed information shall be provided to the Committee staff support prior to the review.

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

XIII. RECORDS

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

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

XIV. CONFIDENTIALITY

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

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

XV. RECOMMENDATIONS

- A. Draft recommendations shall be developed during case review meetings based on issues raised during specific deaths or trends documented from numerous deaths reviewed.
- B. Draft recommendations shall be redistributed for finalization and adoption based on consensus of the Committee during subsequent case review meetings prior to transmission to relevant agencies.
- C. Final recommendations shall be transmitted to relevant agencies and the Office of the City Administrator and/or Mayor within thirty (30) days of finalization/adoption with request for response within sixty (60) days of receipt. Final adopted recommendations shall also be incorporated into the annual report.
- D. Representatives of agencies, institutions and programs may be invited to full Committee meetings to present their plans for, or progress made towards implementing the recommendations.

XVI. COMPENSATION

Members of the Committee shall serve without compensation, except that a public member may be reimbursed for expenses incurred in the authorized execution of official Committee functions, if approved in advance by the Chief Medical Examiner or designee, and subject to the appropriation of and the availability of funds.

XVII. ADMINISTRATION

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

XVIII. LEGAL APPLICATION

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

XIX. RESCISSIONS

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

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



ADRIAN M. FENTY
MAYOR





ACKNOWLEDGEMENT

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

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

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

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*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.***

**GOVERNMENT OF THE DISTRICT OF COLUMBIA
OFFICE OF THE CHIEF MEDICAL EXAMINER, FATALITY REVIEW UNIT
DEVELOPMENTAL DISABILITIES FATALITY REVIEW COMMITTEE**

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