2017

DEVELOPMENTAL DISABILITIES COMMITTEE FATALITY REVIEW ANNUAL REPORT

OFFICE OF THE CHIEF MEDICAL EXAMINER
ROGER A.MITCHELL, JR., M.D.
CHIEF MEDICAL EXAMINER

GOVERNMENT OF THE
DISTRICT OF COLUMBIA
MURIEL BOWSER, MAYOR

DISTRICT OF COLUMBIA
DEVELOPMENTAL DISABILITIES
FATALITY REVIEW COMMITTEE

2017 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

September 2018

TABLE OF CONTENTS

EXECUTIVE SUMMARY

The District of Columbia Developmental Disabilities Fatality Review Committee (hereinafter known as the "DD FRC" or the "Committee") is pleased to present its twelfth Annual Report. The DD FRC 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 2013 - 2017 (N=137)

During the period of 2013 – 2017, the Committee reviewed 137 fatalities of DDS individuals who died between calendar years 2012 through 2017. The following is a summary of the data included in the 2017 Annual Report.

- Of the 137 fatalities reviewed, 117 (85.4%) were attributed to Natural causes.
- Sixty-three (46%) of the individuals were over the age of 60 years.
- Twenty-seven (19.7%) of the individuals were over the age of 70.
- One hundred and seven (78%) of the individuals were African American.
- Sixty-three (46%) of the individuals were Evans Class members.
- Average age at death was 58.3 years.

INTRODUCTION

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

The 2017 Annual Report is a summary of the work performed by the Developmental Disabilities Fatality Review Committee (DD FRC) during calendar years 2013 - 2017. 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 137 fatalities reviewed during the aforementioned years.

The DD FRC 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 DD FRC 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 DD FRC 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

TOTAL MORTALITY FINDINGS

This report addresses the circumstances surrounding the deaths of District residents diagnosed with an intellectual and developmental disability and receive 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 evaluations, based on one or more standardized tests, that document significantly sub average general intellectual functioning (Intelligence Quotient ("IQ") scores of 69 or below), and was diagnosed and/or manifested before the age of 18
- Psychological evaluations that include a formal assessment of adaptive behavior or other supporting documentation of adaptive behavior functioning manifested during the developmental period and reports that indicate the disability existed concurrently with a full scale IQ of 69 or below and reports that indicate the disability continues to adversely impact the individual's life after the age of 18 and
- Psychological and psychiatric evaluations that document any diagnosed psychiatric condition, should one be present (current and historical).

Section I of this Report provides a general overview of decedent demographics for the fatalities that occurred during calendar years 2013 through 2017 and determined to meet the criteria for review by the DD FRC.

Table 1 below 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 2008 through 2017, the number of consumers served ranged from 1,946 to 2,452 (Endnote 1, see page 18), while the number of DDS deaths during the same ten year span ranged from 27 to 38 annually. Percentage of deaths has remained fairly consistent.

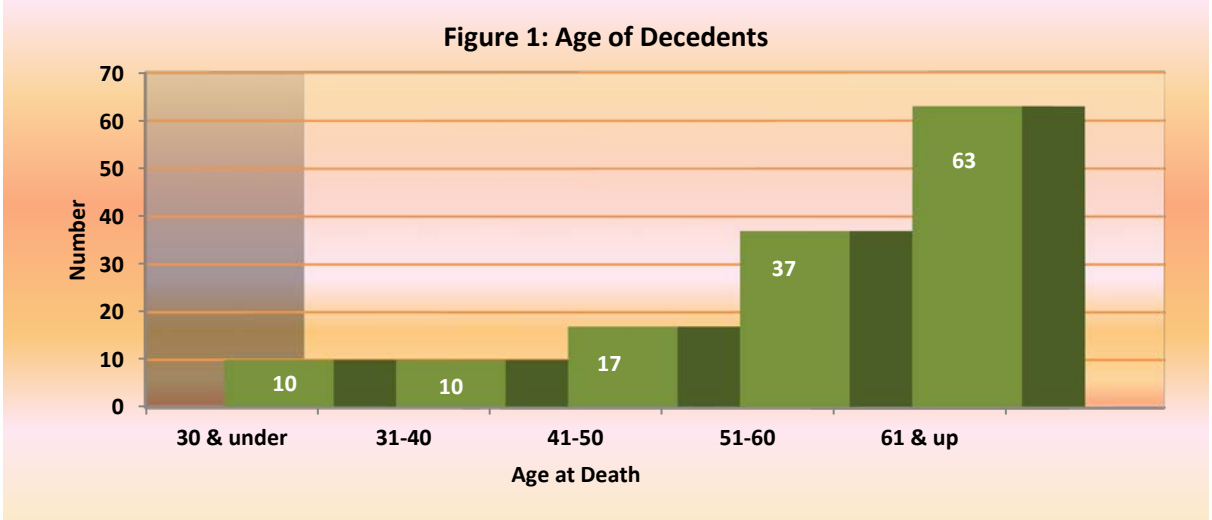
Table 1: District of Columbia DDS Population and Deaths 2008 to 2017

Year	*DDS Population*	*Number of DDS Population Deaths*	*Percentage*
2017	2452	38	1.5%
2016	2397	35	1.5%
2015	2317	34	1.5%
2014	2284	35	1.5%
2013	2248	33	1.5%
2012	2227	37	1.7%
2011	2187	31	1.4%
2010	2026	35	1.7%
2009	1946	29	1.5%
2008	1994	27	1.4%

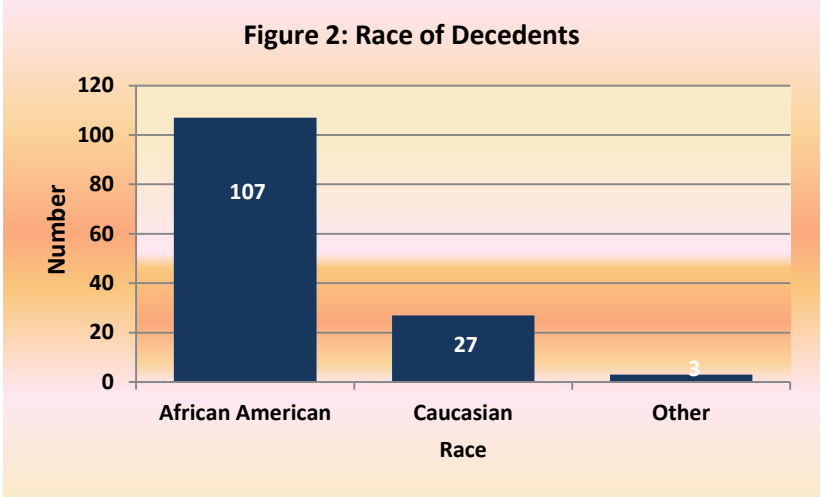
DECEDENT DEMOGRAPHICS - TOTAL MORTALITY POPULATION IDENTIFIED

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 (see Figure 1). The majority of the fatalities reviewed have involved individuals who were in the age group of 61 years or older. Overall, this trend among the DDS population has remained constant since the inception of the fatality review process in 2001. Additionally, the trend among the DDS population is also consistent with the expected national trend of mortality increasing with age for the broader population.



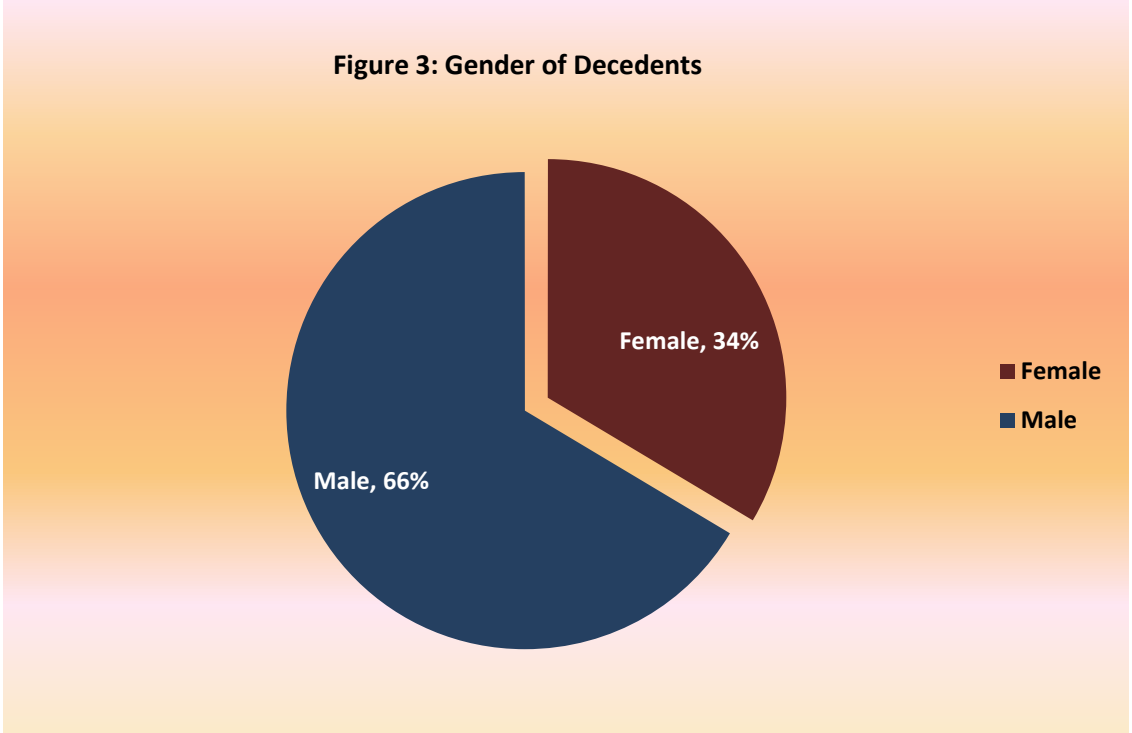
Race of Decedents



Consistent with the overall DDS population, the majority of the DD FRC cases reviewed involved African American decedents (n=107, 78%). Twenty-seven (20%) were Caucasian. The remaining three (2%) were "Other" (Asian, Native American, and Hispanic). See Figure 2.

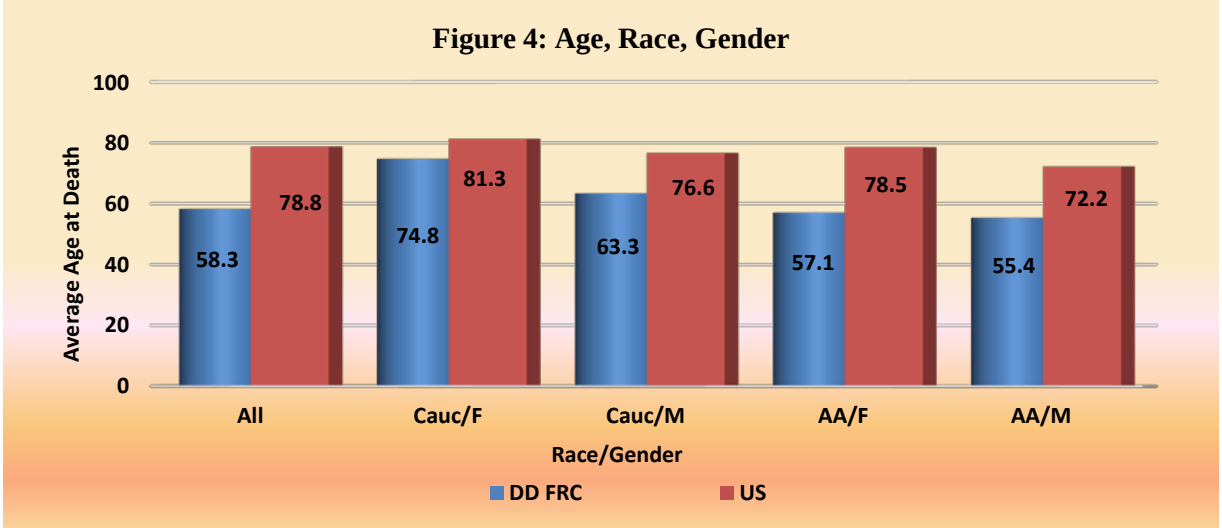
Gender of Decedents

Of the 137 fatalities reviewed, 91 (66%) DD FRC decedents were male and 46 (34%) were female. As seen in Figure 3, the percentage of decedents who were male ranged from 58% - 74% per year, with males consistently representing the majority of decedents.



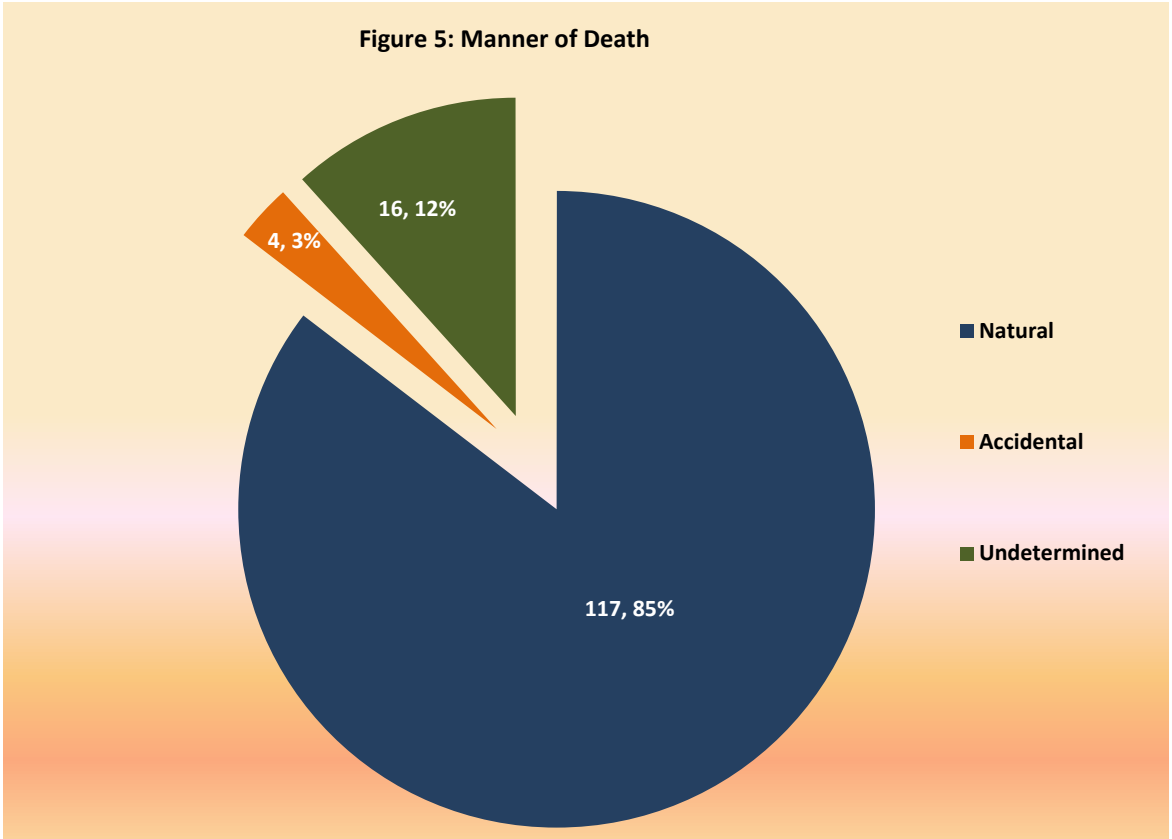
Age, Gender, and Race of Decedents

Figure 4 depicts the interaction between race, gender and age at death. The average age of the decedents at the time of death was 58.3 years. However both race and gender were correlated with age, as were the interactions of race and gender. Though females lived longer than males (avg. age at death 61.3 and 56.8 respectively), Caucasians lived longer than African Americans (avg. age at death 68 and 56 respectively). The figure below shows the cumulative effect of race and gender with African American males dying younger than other race/gender combinations. This pattern closely resembles that among the US population as a whole according to the CDC (2016).



MANNER OF DEATH – TOTAL DEATHS REVIEWED

As illustrated in Figure 5, the leading manner of death for individuals reviewed by the DD FRC is Natural Causes. For this review period, 117 individuals receiving DDS services died of natural causes, four individuals died as a result of Accidents and for 16 individuals the cause of death was Undetermined.



SECTION II:

SUMMARY OF CASE REVIEW FINDINGS BY YEAR

Total fatalities reviewed by the DD FRC Committee during the period 2013 – 2017 equaled 137. Table 2 indicates the number of DD FRC reviewed fatalities during each review period between 2013 and 2017.

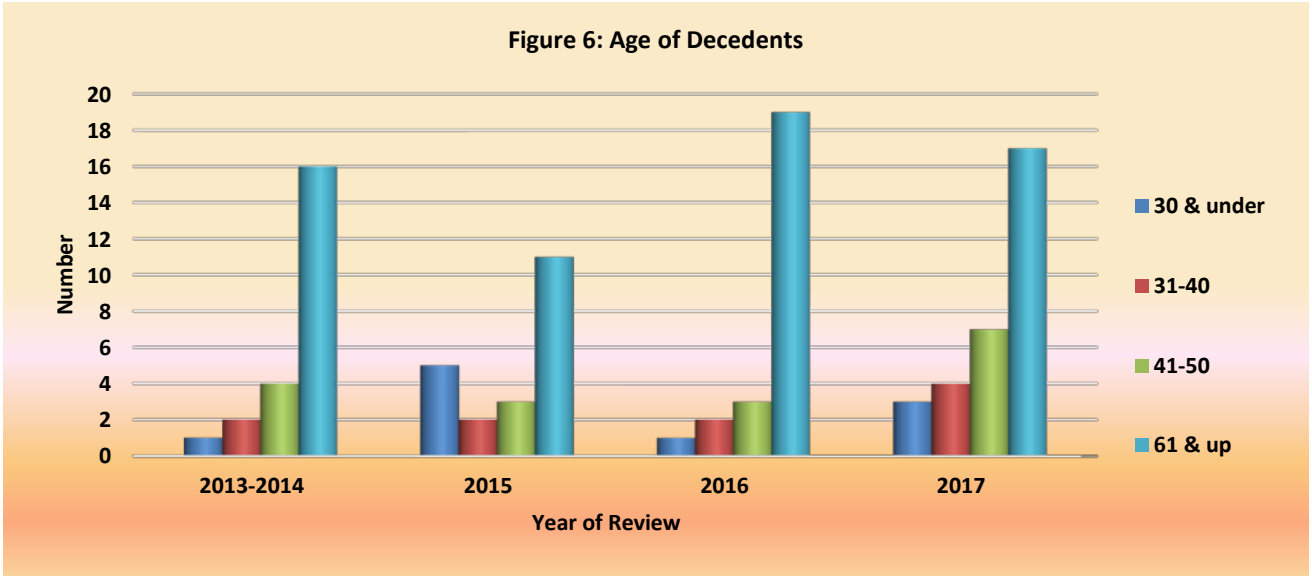
Table 2: Number of Fatalities Reviewed Per Year	
Year of Review	***Number of Fatalities***
2013 – 2014	**37**
2015	**26**
2016	**35**
2017	**39**

DEMOGRAPHICS

Age and Mortality

As Figure 6 illustrates, for each review period most of the decedents were over the age of 61. In each review period other than 2015, increasing age correlates with an increasing number of deaths. During 2015 there were five fatalities (18.5%) in which the decedents were under 31 years of age. This is over twice the average for the entire period of 2013 – 2017 in which only 7% of deaths were of persons under 31 years of age. Average age at death across the 4 review periods ranged from 56 – 62. Table 3 depicts the average age at death and age range for each review periods.

Table 3: Range of Age and Average Age at Death		
Review Period	***Age Range***	***Average Age***
2013 – 2014	**29 - 86**	**58.7**
2015	**23 - 89**	**56**
2016	**29 - 84**	**62**
2017	**20 - 84**	**56.1**



Gender and Mortality

Table 4 depicts the distribution of fatalities across gender of the individuals. In each review period, males outnumbered females. During the review period 2013 – 2014, males represented 68% of the decedents. Similarly, in 2015, 2016, and 2017, they represented 58%, 63%, and 74% respectively.

Table 4: Gender		
Review Period	***Female***	***Male***
2013 - 2014	**12**	**25**
2015	**11**	**15**
2016	**13**	**22**
2017	**10**	**29**

Race and Mortality

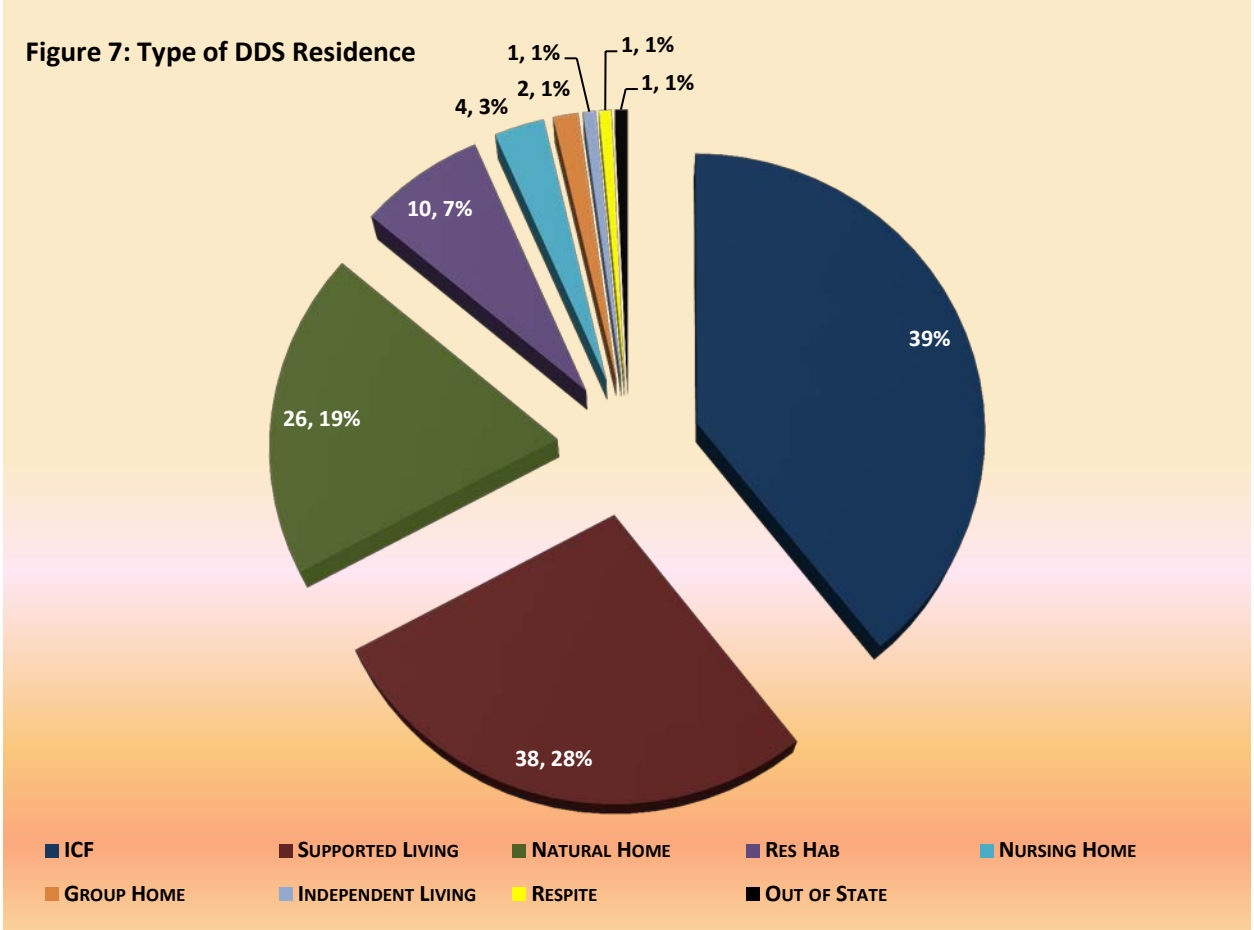
Consistent with previous FRC review years and the overall DDS population served, the majority of the fatalities reviewed in each period were African American. As illustrated in Table 5, 78% of decedents reviewed during the 2013-2014 period were African American. Similarly, in 2015, 2016, and 2017, African Americans represented 85%, 74%, and 77% of fatalities respectively. One decedent during the 2017 review period was Hispanic. During the 2013 – 2014 review periods, one decedent was Asian and one was Native American.

Table 5: Race			
Review Period	***African American***	***Caucasian***	***Other***
2013 - 2014	**29**	**6**	**2**
2015	**22**	**4**	**0**
2016	**26**	**9**	**0**
2017	**30**	**8**	**1**

Type of DDS Residence

The 137 fatalities reviewed involved individuals who resided in their natural homes or community based placements where their specialized needs could be met. As shown in Table 6, the majority of deaths involved decedents living in an ICF home (39%) a Supported Living home (28%), or their Natural Home (19%). During the 2013-2014 review periods, two individuals lived in a ResHab setting and one lived in a nursing home. The same is true of the 2015 review period. During the 2016 review period, in addition to the four people residing in ResHab and the two people in Nursing/Respite Homes, one person resided in a Group Home and one in Independent Living setting. In 2017, thirteen (33%) individuals lived in an ICF home and nine individuals (23%) resided in their natural home where they received individualized Medicaid Waiver services. Twelve individuals (31%) resided in supportive living homes and two (5%) lived in ResHab. One individual (2.5%) received supports in a group home, one (2.5%) in a nursing home, and another (2.5%) was out of state.

Table 6: Type of Residence					
Place of Residence	**2013 - 2014**	**2015**	**2016**	**2017**	**Total**
Natural Home	**6**	**7**	**4**	**9**	**26**
Out of State	**0**	**0**	**0**	**1**	**1**
Supportive Living	**12**	**4**	**10**	**12**	**38**
Group Home	**0**	**0**	**1**	**1**	**2**
Intermediate Care Facility	**16**	**12**	**13**	**13**	**54**
Residential Rehabilitation	**2**	**2**	**4**	**2**	**10**
Nursing/Respite Home	**1**	**1**	**2**	**1**	**5**
Independent Living	**0**	**0**	**1**	**0**	**1**

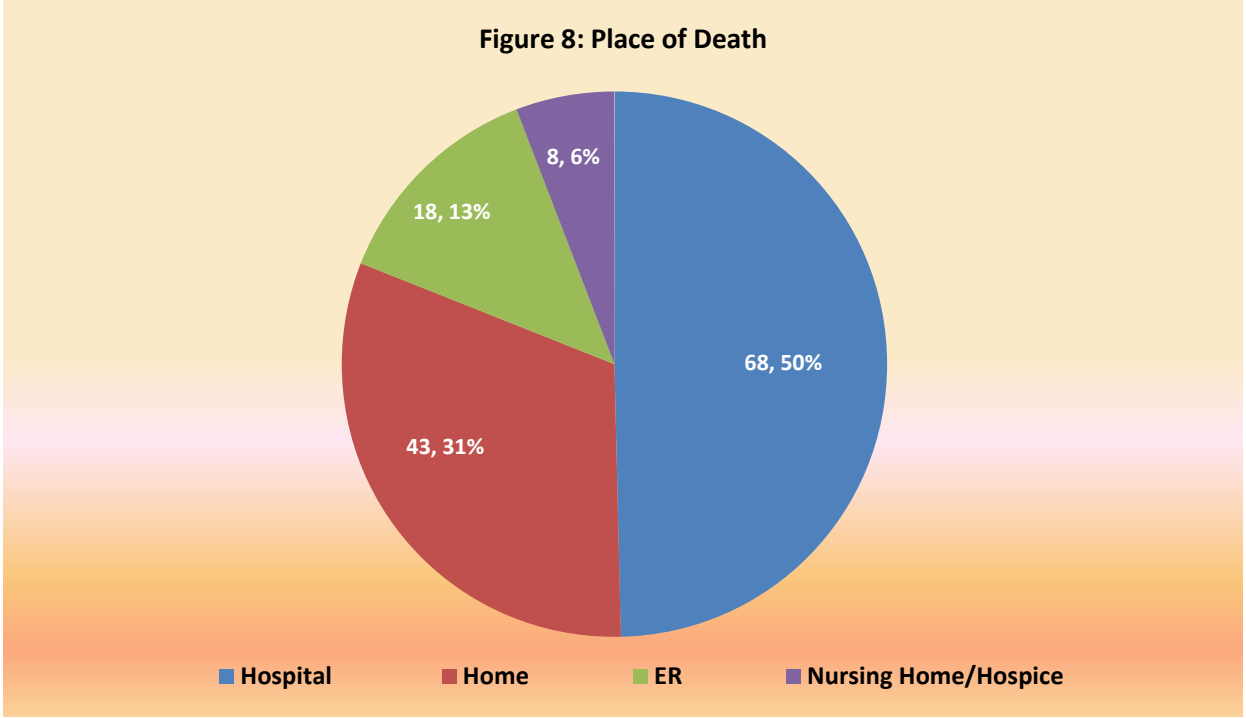


Location of Fatality

The fatality reviews revealed that the deaths occurred in different locations including hospitals, nursing facilities, and residential placements. As depicted in Table 7, the majority of individuals (50%) died during a hospital admission or at their place of residence (31%). A small number of individuals died at a nursing or respite facility (3 in 2013-2014 and 2016, and 2 in 2017). Additionally, 18 were pronounced dead in a hospital emergency room. No trends across review periods were noted. Location of death can provide a measure of health or end of life care received leading up to the fatality.

Table 7: Location of Fatality

Place of Death	*2013 - 2014*	*2015*	*2016*	*2017*	*Total*
Hospital (Inpatient Admission)	20	8	15	25	68
Home	9	9	15	10	43
Emergency Room	5	9	2	2	18
Nursing/Respite Facility	3	0	3	2	8



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 DD FRC include detailed information related to these risks and the Committee considers these factors as part of the case evaluation process.

As depicted in Table 8, based on the 137 fatalities reviewed, 47% of individuals were on a regular textured diet while 26% 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 With regard to the individual's mobility (Table 9) 12 (31%) required no support with mobility, 17 (44%) required the use of a wheelchair. Ten individuals (26%) required support (gait belt, walker, etc.). G-tube, pureed or "mechanical soft" foods were required for the remaining 26% of individuals.

Table 8: Food Textures

Texture	*2013 - 2014*	*2015*	*2016*	*2017*	*Total*
Regular	**18**	**9**	**14**	**24**	**65**
Pureed/Mechanical Soft	**10**	**8**	**14**	**4**	**36**
G-Tube Dependent	**9**	**9**	**7**	**11**	**36**

Table 9: Individual's Method of Mobility

Method of Mobility	*2013 - 2014*	*2015*	*2016*	*2017*	*Total*
Mobile without Support	**11**	**5**	**7**	**12**	**35**
Mobility Requiring Support	**7**	**9**	**8**	**10**	**34**
Mobility Requiring Wheelchair Use	**19**	**12**	**20**	**17**	**68**

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. Eighty-nine of the 137 DD FRC individuals (65%) had one or more mental health diagnoses. Nearly half of the decedents (40%) had two or more mental health diagnoses.

Table 10: Individual's Mental Health Diagnoses		
Mental Health Diagnoses	Number of Decedents	Percent of Decedents
0	48	35%
1 or more	89	65%
2 or more	55	40%
3or more	24	17.5%
4 or more	6	4.4%

Mental Health diagnoses ranged from Autism to Anxiety Disorders to Psychotic Disorders. The graph below represents the category of diagnoses, rather than the individual diagnoses. A numerical list of these disorders is provided in Figure 7 below.

Figure 7: Decedent Mental Health Diagnoses

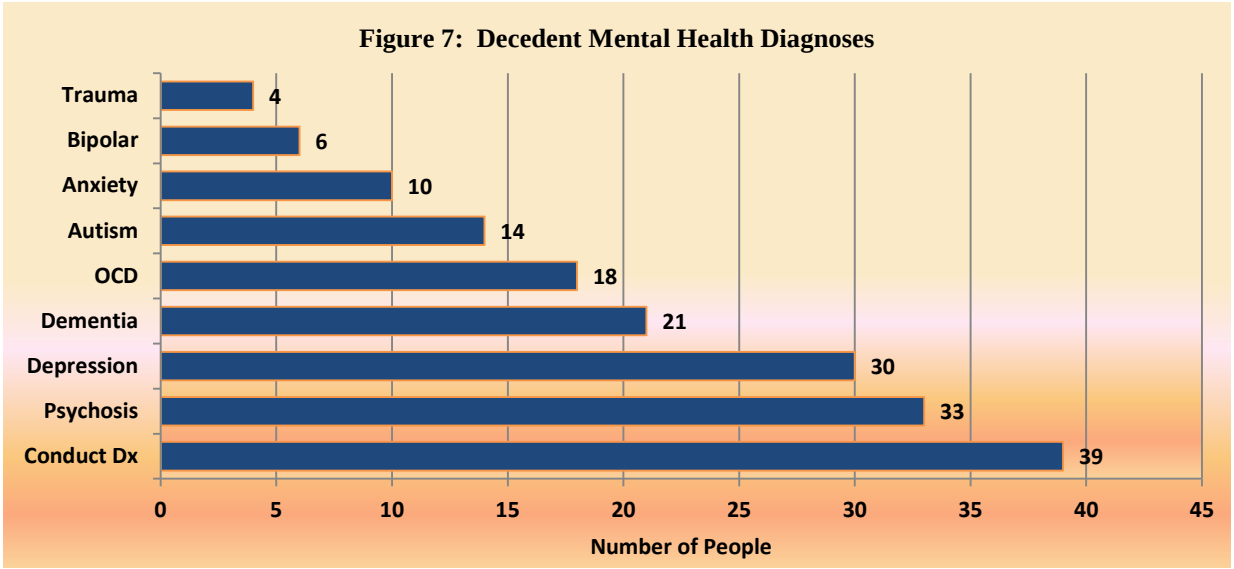


Table 11 provides the individual's level of functioning as related to intellectual disability as provided in the mortality investigative report.

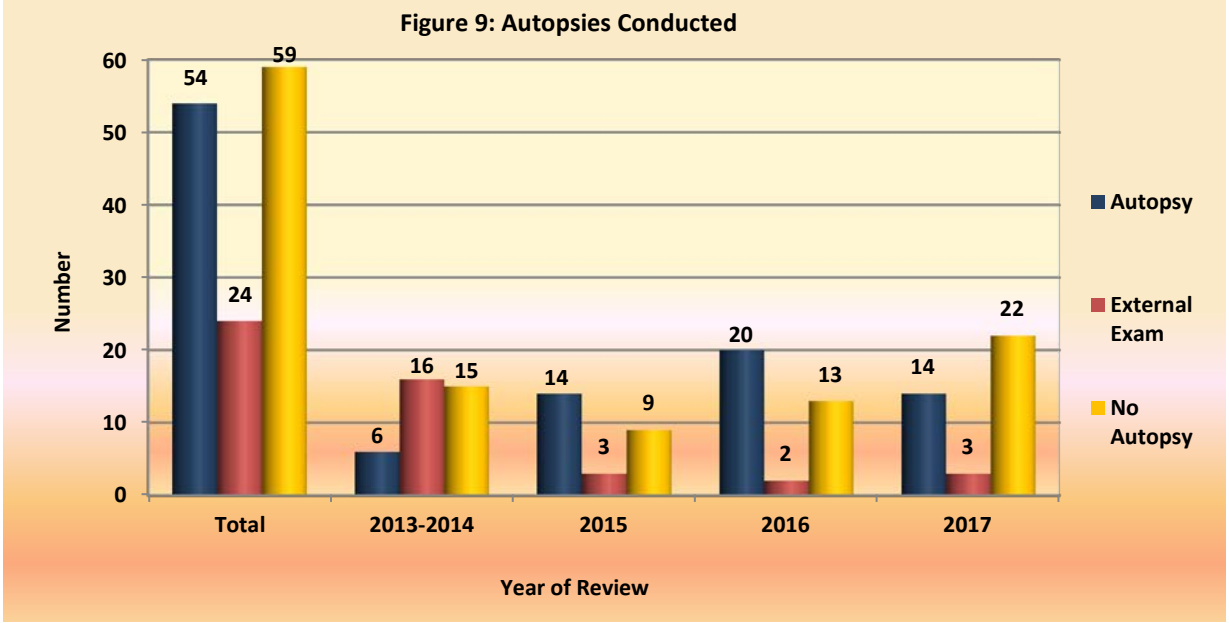
- Profound Intellectual Disability: Individuals require high levels of supervision and structure with activities of daily living.
- Severe Intellectual Disability: Individuals may have some self-care and communication skills however will also need supervision and a structured living environment.
- Moderate 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 11: DDS FRC Individual's Cognitive and Adaptive Level of Functioning		
Level of Functioning	**Cognitive**	**Adaptive**
Profound	**14**	**14**
Severe	**7**	**7**
Moderate	**9**	**9**
Mild	**6**	**4**
Borderline	**1**	**-**
Unknown	**-**	**2**

MANNER AND CAUSE OF DEATH

Autopsies

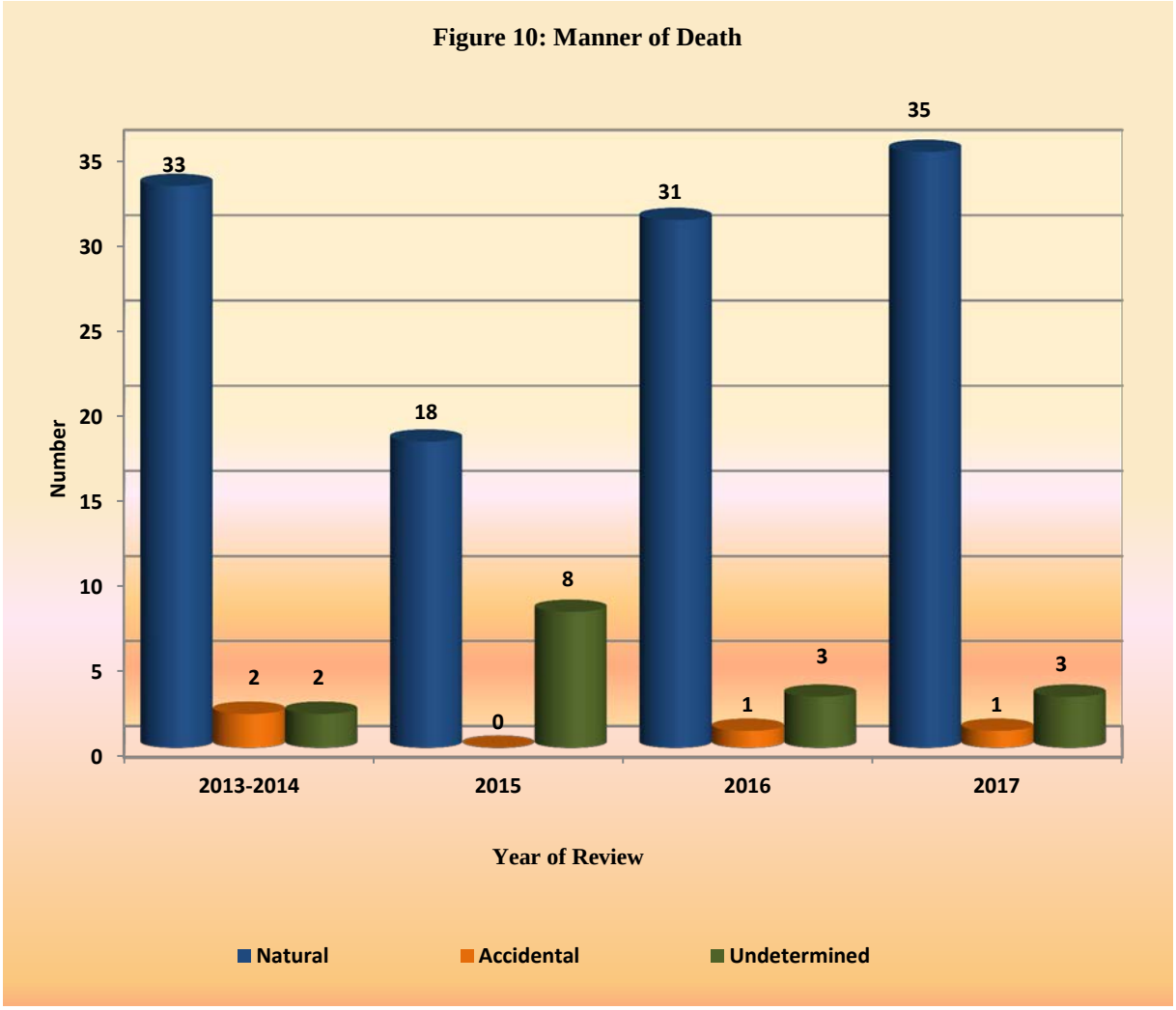
Figure 9 depicts the number of autopsies conducted per year. Of the 39 deaths reviewed in 2017, 13 had an autopsy completed and 4 an external exam only. Twenty-two decedents had neither an autopsy nor external exam. The determination of when an autopsy is performed is made by the attending pathologist. An autopsy may be done when there are potential competing causes of death, when the death is sudden or unexpected, when the manner of death is determined to be other than Natural, or when the examination is mandated by law (i.e. Evans Pratt cohort).



Manner of Death

There are five (5) manners of death including homicide, suicide, accident, natural or undetermined. The manner of death, as determined by the forensic pathologist, is an 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. Consistent with previous years, the majority of the 39 fatalities of DD FRC individuals reviewed in 2017 were determined to be natural deaths (N=35), while one fatality was determined to be an accident. The manners of death of three individuals were Undetermined.

Figure 10: Manner of Death



Cause of Death

Table 12 provides a list of the causes of death associated with the 137 fatalities reviewed between 2013 and 2017. The majority of the DD FRC individuals died as a result of cardiovascular disease (35%), followed by Respiratory Disease (25%). The cause of death in six cases was unknown. No significant trends, either increasing or decreasing, were noted in the frequency of death due to a given cause.

Table 12: Causes of Death

Cause of Death	*2013 - 2014*	*2015*	*2016*	*2017*	*Total*
Cardiovascular System Disorder	**12**	**10**	**11**	**15**	**48**
Respiratory Disease	**8**	**10**	**8**	**8**	**34**
Cancer	**4**	**2**	**4**	**4**	**14**
Genetic Disorder	**2**	**0**	**2**	**4**	**8**
Infectious Disease	**4**	**0**	**1**	**3**	**8**
Unknown	**2**	**1**	**3**	**0**	**6**
Gastrointestinal System	**1**	**1**	**2**	**2**	**6**
Multi-system Organ Failure	**0**	**1**	**1**	**1**	**3**
Asphyxia	**1**	**0**	**0**	**1**	**2**
Diabetes	**1**	**0**	**0**	**1**	**2**
Blunt Impact	**1**	**0**	**1**	**0**	**2**
Renal System	**1**	**0**	**1**	**0**	**2**
Sepsis	**0**	**1**	**1**	**0**	**2**

SECTION III:
Recommendations
and
Committee Discussions

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 trends in recommendations are frequently made. These may include recommendations for action by DDS or by specific provider agencies. The most commonly listed recommendations for the review period 2013 – 2017 are listed here.

Recommendations Based on Deaths Reviewed in 2013 - 2014
Ensure the DDS SCs are completing the required minimum frequency of face-to-face visits, documenting contact and following up on issues of concern as per generally accepted practice;
Health Passports are complete, accurate, and up-to-date as per generally accepted practice;
HCMPs are complete, accurate, and up-to-date as per generally accepted practice;
End-of-life planning is completed for all individuals supported or the rationale for not completing this planning is clearly documented as per generally accepted practice;
All physician orders and physician recommendations are implemented 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;
All evaluations and assessments are up-to-date, and that the recommendations are implemented or the rationale for not implementing the order/recommendation is clearly documented as per generally accepted practice;
All weight and seizure activity logs/tracking forms are completed and maintained as indicated as per generally accepted practice;
The use of outdated terminology (i.e., mental retardation, diapers, feeding, etc.) is discontinued as per generally accepted practice.
All staff members are adequately trained to perform CPR as per generally accepted practice.
Recommendations Based on Deaths Reviewed in 2015
Health Passports and HCMPs are complete, accurate, and up-to-date as per DDA Health and Wellness and Standard 1: Health Passport and Standard 5: HCMP;
Adequate coordination, communication, and/or exchange of information occurs between PCPs and other medical specialists as per generally accepted practice;
End-of-life planning is completed for all individuals supported or the rationale for not completing this planning is clearly documented as per DDA Health and Wellness and Standard 24: End-of-Life Planning;
All physician orders and physician recommendations are implemented 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;
All evaluations and assessments are up-to-date as per generally accepted practice;
All bowel movement, weight, vital signs, and seizure activity logs/tracking forms are completed and maintained as indicated as per generally accepted practice;
All nutritional supplements and diet orders are documented on the MARs and Physician's Orders as per DDA Health and Wellness and Standard 17: Medication Prescription and Administration;
Sufficient and accurate historical medical information is provided to hospitals and/or medical specialists

as per generally accepted practice;
All medication indications are listed on the MARs as per DDA Health and Wellness and Standard 17: Medication Prescription and Administration;
That psychotropic medication reduction plans are addressed and/or the rationale for not addressing this is clearly documented as per DDA Health and Wellness and Standard 17: Medication Prescription and Administration;
The use of outdated terminology (i.e., mental retardation, diapers, feeding, etc.) is discontinued as per generally accepted practice.
Recommendations Based on Deaths Reviewed in 2016
All evaluations and assessments are accurate and up-to-date as per generally accepted practice;
HCMPs and Health Passports are complete, accurate, and up-to-date as per DDA Health and Wellness and Standard 1: Health Passport and Standard 5: HCMP;
All agency staff are sufficiently trained and determined competent to recognize life-threatening changes in a person's wellbeing and when to independently initiate calling EMS/911 as per generally accepted practice;
All agency staff are sufficiently trained and determined competent to recognize changes in an individual's condition, to collect vital signs, to make meaningful observations, and to effectively and promptly communicate that information to nursing staff as per generally accepted practice;
End-of-life planning is completed for all individuals supported or the rationale for not completing this planning is clearly documented as per DDA Health and Wellness and Standard 24: End-of-Life Planning;
All medication indications are listed on the MARS and the physician orders as per DDA Health and Wellness and Standard 17: Medication Prescription and Administration;
All medications and/or medication dosages are accurately listed on the MARs, Health Passport, and/or other pertinent records as per DDA Health and Wellness and Standard 17: Medication Prescription and Administration and Standard 1: Health Passport;
Nursing assessments are promptly completed when a person has a significant change in condition as per generally accepted practice;
The use of outdated terminology (i.e., mental retardation, diapers, feeding, etc.) is discontinued as per generally accepted practice;
That a person's level of intellectual disability is accurately documented in all pertinent records as per generally accepted practice.
Recommendations Based on Deaths Reviewed in 2017
Health Passports and HCMPs are complete, accurate, and up-to-date as per DDA Health and Wellness and Standard 1: Health Passport and Standard 5: HCMP;
That a person's level of intellectual disability is accurately documented in all pertinent records as per generally accepted practice;
End-of-life planning is completed for all individuals supported or the rationale for not completing this planning is clearly documented as per DDA Health and Wellness and Standard 24: End-of-Life Planning;
All agency staff are sufficiently trained and determined competent to recognize life-threatening changes in a person's wellbeing and when to independently initiate calling EMS/911 as per generally accepted practice;
All agency staff are sufficiently trained and determined competent to recognize changes in an individual's

condition, to collect vital signs, to make meaningful observations, and to effectively and promptly communicate that information to nursing staff as per generally accepted practice;
All staff members are adequately trained to perform CPR as per generally accepted practice.

Developmental Disabilities Fatality Review Committee Discussions

The DD FRC members discussed several prevailing issues during monthly case review meetings and identified the following reoccurring themes:

- Ensuring accurate and detailed documentation of the individual's medical history within the Health Passport and internal DDS Consumer Information System records that includes their current medical diagnoses and medications. This also includes the provider's documentation of physician's recommendations and communication with the provider's medical staff.
- Discussion and implementation of "end of life" planning for individuals served through DDS.
- Addressing the continuing education needs of providers and nursing staff servicing individuals with disabilities.

Documentation of Individual's Health Records

The services provided to individuals with disabilities through the District of Columbia's Department on Disabilities Services are governed through the agency's Health and Wellness Standards, the Health Passport, Health Care Management Plan and the Individual Service Plan. These tools are utilized to communicate the individual's health needs to their service coordinators, residential providers and medical team. Committee members agree that accurate documentation of the individuals' medical history is critical for positive health outcomes. Forty-five percent (45%, 17) of the recommendations provided to DDS during this five-year review period addressed the accuracy of documentation within the individual's Health Passports and Health Care Management Plans as required by the Health and Wellness Standards.

DDS has ensured that improvements in the accuracy of the documentation of the individual's medical history are ongoing. Service Coordinators update the individual's case notes in accordance with the residential provider's monitoring schedule. DDS Quality Improvement Specialists conduct on-site reviews of the individual's residential provider's records to ensure communication between the individual's primary care physician, medical specialist and the provider's staff nurse remains fluid. The Quality Improvement Specialist also ensures recommendations from medical specialist (e.g. cardiologist, nephrologist, etc.) as well as reasons for alternative recommendations from the primary care physician are communicated with the provider's nurse and accurately documented.

End of Life Planning

End of life planning provides an opportunity for individuals and loved ones to communicate their health care decisions when death is imminent. Critical matters such as do not resuscitate and/or do not intubate orders and desires for palliative care can be addressed through advanced directives. As discussed during DD FRC meetings, many individuals may not be prepared to discuss end-of life planning due to the difficultly of the subject. Utilizing the DDS' *Thinking Ahead* packet, individuals are encouraged to prepare and document their final plans. Also, DDS' Service Coordinators discuss end-of-life planning with individuals during annual service planning meetings.

For individuals with court-appointed guardians, case review discussions identified issues regarding the guardians' lack of participation in end-of life planning and mortality investigations. As guardians sited conflicts with the termination of their authority at the time of the individual's death, Committee members sent a letter to the DC Superior Court Probate Division to ask that the Court and the Guardian Assistance Program consider the following:

- The implementation of periodic training for guardians regarding end-of-life planning.
- The issuance of either an administrative order or a court rule that requires guardians to cooperate with government investigations regarding the death of their wards.

Through DDS' partnership with the Georgetown University Developmental Disabilities Administration Health Initiative, community-based resources are available to assist individuals, their families, court- appointed guardians and advocacy professionals with end-of-life planning.

Continuing Education for Residential Providers

DDS' contracted residential providers and their direct-service staff provide a myriad of hands-on services to individuals throughout the course of their residential life. Committee members agreed that direct service providers should be provided with opportunities for continuing education on issues affecting this vulnerable population, in addition to those education requirements of licensed direct-service staff. This includes CPR training, recognizing changes in an individual's health condition and accurate documentation. Through their ongoing support of individuals and their residential providers, DDS Quality Improvement Specialists review contracted residential provider records to ensure direct-service staff meets requirements for licensure and required training. Furthermore, the Georgetown University's Developmental Disabilities Administration Health Initiative provides thematic training for direct-service staff to address the needs of individuals served through DDS.

Looking Forward

In the upcoming review year, the DD FRC will take a closer look at two issues affecting the well-being of individuals served by DDS; the prevalence of gastrointestinal problems among this population and the needs of individuals residing within their natural home setting. In 2016 staff for the DD FRC was asked to collect data on the top five medical issues affecting this population of decedents. Following hypertension and cardiovascular issues, digestive issues stood out as a

medical problem leading to the natural death of individuals served. Chronic medical histories of gastrointestinal reflux and dysphagia were challenging diagnoses primarily due to the individual's congenital, neurological and gastro-motility issues. The DD FRC will develop findings and recommendations to address how to train residential providers and their direct-service staff on the special needs of individuals with gastrointestinal problems as a tool to prevent these deaths.

Individuals who are able to reside within their natural home with their families encompass the most ideal living arrangement. DDS is focusing on supporting families caring for individuals within the home setting. This includes the implementation of the Family Team Meeting process with service coordinators to document the needs of the family. Training for relative caretakers will also be an option to maintain the family home-setting. Through its review of deaths of individuals within their natural home, the DD FRC will develop recommendations that will assist DDS in their endeavor to improve outcomes for individuals residing within their natural home setting.

APPENDICES

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/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	Individuals 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 individuals with developmental or intellectual disabilities with drop-in twenty-four hour supervision. Supervised apartments may be single units grouped in a cluster within an apartment complex, or scattered throughout a complex

CAUSES OF DEATH 2013 - 2017 DD FRC DEATHS REVIEWED

Deaths Reviewed that Occurred in 2012		
Age/Race/Sex	Cause of Death	Manner of Death
68/AfAm/M	Down syndrome	Natural
54/AfAm/F	cardiorespiratory failure	Natural
Deaths Reviewed that Occurred in 2013		
Age/Race/Sex	Cause of Death	Manner of Death
40/AfAm/F	aspiration pneumonia	Natural
52/AfAm/M	acute respiratory failure	Natural
48/NaAm/M	complications of cerebral palsy	Natural
50/AsAm/M	hepatic cirrhosis from Hepatitis B	Natural
59/AfAm/M	intracerebral hemorrhage	Natural
66/AfAm/M	OSA with PHTN, community acquired PNA, COPD, intellectual disability, and schizophrenia	Natural
55/AfAm/M	asphyxia, due to aspiration of food that occluded his airway	Accidental
55/AfAm/F	fatal arrhythmia	Natural
63/AfAm/M	Down syndrome	Natural
57/AfAm/M	sepsis, acidosis secondary to liver failure, and gram negative bacteria	Natural
62/Cauc/F	esophageal cancer	Natural
51/AfAm/F	chronic kidney disease	Natural
57/Cauc/M	chronic respiratory failure	Natural
76/AfAm/M	CHF secondary to hypertensive and arteriosclerotic cardiovascular disease	Natural
64/AfAm/F	complications of chronic colitis	Natural
29/AfAm/F	unknown	Undetermined
49/AfAm/M	complications of remote stroke due to arteriosclerotic cerebrovascular disease	Natural
37/AfAm/M	diabetic ketoacidosis	Natural
65/AfAm/M	cardiopulmonary arrest	Natural
Deaths Reviewed that Occurred in 2014		
Age/Race/Sex	Cause of Death	Manner of Death
62/AfAm/M	hypertensive and arteriosclerotic cardiovascular disease with dialysis dependent chronic renal disease	Natural
86/Cauc/F	malignant cancer of bronchus and lung	Natural
59/AfAm/M	pulmonary embolism	Natural
83/AfAm/F	aspiration of nasal gastric contents, gastrostomy tube, adult failure to thrive and hypertensive cardiovascular disease.	Natural
67/Cauc/M	aplastic anemia of unknown etiology	Natural
51/AfAm/M	pulmonary embolism	Undetermined
55/AfAm/M	metastatic adenocarcinoma of unknown primary	Natural
66/AfAm/M	anoxic brain injury, myocardial infarction, and essential hypertension	Natural
57/AfAm/F	respiratory failure due to aspiration	Natural
28/AfAm/F	failure to thrive due to cerebral palsy with intellectual disability	Natural
41/AfAm/M	hit by car	Accidental
63/AfAm/M	sepsis shock and aspiration pneumonia	Natural
56/Cauc/F	respiratory failure due to pneumonia	Natural
81/AfAm/F	cardiac arrest	Natural
68/Cauc/M	septic shock and Clostridium difficile colitis	Natural

63/AfAm/M	community-acquired pneumonia complicated by spastic quadriplegia following pediatric measles encephalitis	Natural
57/AfAm/M	cardiopulmonary arrest	Natural
49/AfAm/M	complications of aspiration pneumonia	Natural
62/AfAm/M	complications of aspiration pneumonia	Undetermined
89/AfAm/F	hypertensive and arteriosclerotic cardiovascular disease	Natural
23/AfAm/M	cardiac arrest	Undetermined
65/AfAm/F	metastatic breast cancer	Natural
43/AfAm/M	cardiac arrest	Undetermined
85/AfAm/F	hypertensive cardiovascular disease	Natural
54/AfAm/M	complications of acute bowel obstruction due to adhesions from remote abdominal surgery	Natural
75/AfAm/M	cardiopulmonary arrest due to sepsis, and upper gastrointestinal bleed	Undetermined

Deaths Reviewed that Occurred in 2015

Age/Race/Sex	Cause of Death	Manner of Death
39/AfAm/F	acute and chronic respiratory failure	Undetermined
54/AfAm/F	hypertensive cardiovascular disease with contributory cause of intellectual disability, seizure disorder, multiple meningiomas, and stroke.	Natural
40/AfAm/M	hepatocellular carcinoma	Natural
42/AfAm/M	cerebral palsy, refractory seizure disorder, cognitive disability, and sinus tachycardia, anemia of chronic disease, ataxia, dysphagia, and prior aspiration pneumonia	Natural
56/Cauc/M	Acute respiratory failure due to aspiration pneumonia	Natural
56/AfAm/F	fatal cardiac arrhythmia	Natural
76/Cauc/F	atherosclerotic cardiovascular disease	Natural
68/Cauc/M	respiratory failure, exacerbation of asthma and restriction	Natural
83/Cauc/F	acute respiratory failure due to or as a consequence of COPD exacerbation	Natural
26/AfAm/F	"Respitory issues"	Undetermined
65/AfAm/F	hypertensive cardiovascular disease with other conditions of seizure disorder, subacute cerebral infarcts, and chronic obstructive pulmonary disease	Natural
30/AfAm/M	hyperthermia complicated by conduction systems abnormalities	Undetermined
76/AfAm/F	cardiopulmonary arrest, acute or chronic renal failure, and hyperkalemia	Natural
50/Cauc/M	persistent respiratory failure following subtotal colectomy for treatment of multifocal adenocarcinoma of the colon	Natural
73/AfAm/M	aspiration pneumonia	Natural
77/AfAm/M	unknown	Natural
59/AfAm/M	acute respiratory failure due to community acquired pneumonia	Natural
28/AfAm/M	cardiac arrest	Undetermined
40/AfAm/F	cardiorespiratory failure due to underlying genetic conditions	Natural
29/AfAm/M	bacteremia, fungemia, ARDS, and eventual multisystem organ failure	Undetermined
68/AfAm/F	healthcare acquired pneumonia in the setting of chronic respiratory failure	Natural
62/Cauc/M	acute aspiration pneumonia, due to sepsis, due to bowel obstruction with Down syndrome	Natural
58/AfAm/M	unknown	Undetermined
54/AfAm/F	cardiopulmonary arrest	Undetermined
69/Cauc/M	aspiration pneumonia in the setting of hiatal hernia and gastroesophageal reflux disease	Natural
58/AfAm/M	multiple blunt force injuries	Accident
62/AfAm/M	sepsis due to aspiration pneumonia	Natural
70/AfAm/F	complications of right hemicolectomy	Natural
61/AfAm/M	cardiac arrest	Natural
77/Cauc/M	respiratory failure due to abdominal compartment syndrome due to intestinal obstruction	Natural

80/Cauc/M	cause not obtained	Natural
60/AfAm/M	sepsis	Natural
50/AfAm/M	coronary artery disease	Natural

Deaths Reviewed that Occurred in 2016

Age/Race/Sex	Cause of Death	Manner of Death
84/Cauc/F	cardiopulmonary arrest due to congestive heart failure	Natural
61/AfAm/M	hypertensive cardiovascular disease,	Natural
32/AfAm/M	metastatic colon cancer and familial adenomatous	Natural
55/AfAm/F	hypertensive and atherosclerotic cardiovascular disease	Natural
60/AfAm/M	acute bronchopneumonia	Natural
81/AfAm/M	pulmonary fibrosis	Natural
63/AfAm/M	failure to thrive	Natural
56/Cauc/F	metastatic adenocarcinoma, probable gallbladder primary	Natural
56/AfAm/F	metastatic pancreatic cancer	Natural
68/AfAm/F	hypertensive atherosclerotic cardiovascular disease	Natural
81/AfAm/M	unknown	Natural
72/Cauc/M	Down syndrome and the consequences thereof.	Natural
55/AfAm/F	non-traumatic subdural hemorrhage	Natural
47/AfAm/M	chronic renal failure with a significant other contributing condition of Crohn disease	Natural
62/AfAm/M	pneumonia and CHF	Natural
84/AfAm/F	hypertensive, atherosclerotic, and valvular cardiovascular disease with other conditions of dementia and diabetes mellitus	Natural
58/AfAm/M	metastatic gastric carcinoma	Natural
81/Cauc/F	hypertensive cardiovascular disease with contributing causes of sick sinus syndrome, diabetes mellitus, anemia, and vascular dementia.	Natural
56/AfAm/M	acute respiratory failure and aspiration pneumonia	Undetermined
56/AfAm/M	ventricular tachycardia, acute myocardial infarction, and coronary artery disease	Natural
45/AfAm/F	cardiomegaly with contributing causes of mitral valve prolapse, sinus bradycardia, and obesity	Natural
78/Cauc/F	hypertensive, valvular, and arteriosclerotic cardiovascular disease	Natural
36/AfAm/F	acute respiratory distress syndrome, aspiration pneumonia, and anoxic brain injury	Natural
62/Cauc/M	sepsis due to aspiration pneumonia and complicating dysphagia associated with profound intellectual disability	Natural
70/AfAm/M	complications of cerebral palsy with contributing factors of hypertension, and valvular and arteriosclerotic cardiovascular disease	Undetermined
82/AfAm/M	complications of pica, including bowel bezoar(s), obstruction, volvulus, and rupture of surgical anastomosis.	Natural
68/AfAm/M	community acquired pneumonia with contributory causes of history of Down syndrome, cerebral palsy, and seizure disorder	Natural
54/AfAm/M	respiratory failure secondary to anemia and thrombocytopenia	Natural
69/AfAm/M	cardiopulmonary arrest and chronic obstructive pulmonary disease	Natural
23/AfAm/M	acute myeloid leukemia, diabetes, and Down syndrome with another significant condition of pulmonary embolus	Natural
34/AfAm/M	sepsis, due to aspiration pneumonia, due to cerebral palsy, not otherwise specific with a significant condition of gastrointestinal bleeding	Natural
77/AfAm/M	hemoperitoneum complicating metastatic malignant melanoma	Natural
84/Cauc/F	complications following right hip fracture with contributory causes of: hypertensive and cardiovascular disease, congestive heart failure, atrial fibrillation, diabetes mellitus and chronic kidney disease	Undetermined
63/AfAm/M	failure to thrive	Natural
75/AfAm/M	failure to thrive and recurrent aspiration pneumonia with dysphagia and dementia and a contributing condition of Down syndrome	Natural

49/AfAm/M	cardiogenic shock due to or as a consequence of non-ischemic cardiomyopathy	Natural
55/AfAm/M	parenchymal hemorrhage	Natural
58/AfAm/M	hypertension and atherosclerotic cardiovascular disease with a contributing condition of a seizure disorder of unknown etiology	Natural
46/AfAm/F	acute right heart failure and pulmonary embolism	Natural
62/Cauc/M	peritonitis due to gastric fistula complicating percutaneous endogastric tube placement with a contributing cause of intellectual disability	Natural
Deaths Reviewed that Occurred in 2017		
Age/Race/Sex	Cause of Death	Manner of Death
45/AfAm/M	Non-Hodgkin's lymphoma	Natural
38/AfAm/M	protein S deficiency	Natural
55/Cauc/M	aspiration pneumonia due to neurogenic of non-traumatic origin	Natural
66/Hisp/M	leg ulcer; poor circulation; and history of poliomyelitis	Natural
67/AfAm/M	hypertensive and atherosclerotic cardiovascular disease with myocardial infarction	Natural
77/AfAm/M	congestive heart failure	Natural
45/AfAm/F	hypoxic respiratory failure; community acquired pneumonia; and Down syndrome	Natural
52/Cauc/M	cardiopulmonary arrest, aspiration pneumonia, and severe developmental delays	Natural
47/AfAm/F	anomalous origin of the coronary arteries with a contributing condition of hypertensive cardiovascular disease.	Natural
56/Cauc/M	asphyxia due to choking with a significant condition of cerebral palsy	Accidental
65/AfAm/F	complications from aspiration pneumonia	Natural
20/AfAm/M	complicated from San Filippo syndrome	Natural
37/AfAm/M	diabetic ketoacidosis	Natural
49/AfAm/M	hypertensive cardiovascular disease	Natural
68/AfAm/F	complications of cholangiocarcinoma	Natural
25/AfAm/M	propionic acidemia of 25 years duration	Natural
77/Cauc/F	cardiopulmonary arrest and bladder cancer	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 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

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

ATTEST: _____
STEPHANIE D. SCOTT
SECRETARY OF THE DISTRICT OF COLUMBIA

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.

Government of the District of Columbia
Office of the Chief Medical Examiner,
Fatality Review Unit
Developmental Disabilities Fatality Review Committee
401 E Street SE
Washington, D.C. 20024