DDS
Mortality Review Committee
Fiscal Year 2017
Report

September 30, 2018

I. Introduction

This Mortality Review Committee 2017 Fiscal Year Report is a summary of the work performed by the District of Columbia Department on Disability Services (DDS) Mortality Review Committee, which conducts DDS internal mortality case reviews. The MRC is charged with examining the events surrounding the deaths of individuals who were receiving services from (DDS) at the time of their death. The DDS MRC 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 persons who receive services and or supports from DDS. One goal of the DDS MRC is to identify trends and make recommendations to improve the supports and services received by the eligible residents of the District of Columbia.

The committee membership is a representation of a range of disciplines including public and private agencies. Membership includes representation from DDS Health and Wellness Division, Service Planning and Coordination Division, DC Coalitions of Disability Service providers, Georgetown University initiative, Quality Trust for Individuals with Disabilities, Department of Health Care Finance, DDS provider community and persons receiving services from DDS. The primary function of the DDS MRC involves the collection, review, and analysis of individual's death-related data in order to identify consistent patterns and trends, which assist in increasing knowledge related to risk factors and guiding system change/enhancements. The mortality review process includes the examination of an independent investigative report of each individual's death that includes a summary of the forensic autopsy reports or death certificate, the individual's social history, living conditions prior to death; medical diagnoses, 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.

The analysis of the data is based on the **37** mortality investigation cases reviewed between October 1, 2016 and September 30, 2017. The mortality investigation case summaries were conducted and provided by *The Columbus Organization*. DDS provides life-long services to eligible residents of the District of Columbia; therefore, mortality cases will inevitably be reported on aging persons receiving our services. The purpose of this report is to provide a brief overview, of the DDS Mortality Review Committees process and the tracking of repeated committee recommendations.

II. The Number of DC DDS Reviewed Mortality Cases:

Case Reviewed

There were a total of 37 mortality cases reviewed by the Mortality Review Committee between October 1, 2016 and September 30, 2017. Twenty-Eight (28) of the 37 decedents were male. There was a significantly higher number of deaths among African-American (29) compared to Caucasians (7). Though females lived longer than males (avg. age at death (61.3 and 56.8 respectively). Caucasians lived longer than African Americans (avg. age 68 and 56 respectively). This pattern closely resembles that among the US population as a whole according to the CDC (2016). The average life expectancy for Americans is 78.7 years according to Organization for Economic Cooperation and Development (OECD). The average age of death for persons receiving services from DDS for FY 17 was 57 years.

III. Findings

A. Trends/Patterns

The following trends/patterns were found after reviewing the 37 mortality investigation reports for the above noted people.

Race:

- 29 people (or 78%) were African-American
- 7 people (or 19%) were Caucasian
- 1 person (or 3%) was Hispanic

During FY17, DDS supported 2,396 people. Of this number, 1,892 people (or 79%) were African-American, 141 people (or 6%) were Caucasian, 56 people (or 2%) were Hispanic, and 307 people (or 13%) were other races (Asian, Native American, unknown, or other).

Sex:

- 28 people (or 76%) were male
- 9 people (or 24%) were female

During FY17, 1471(or 61%) of the 2396 supported were male and 925 (or 39%) were female.

Age Range:

- 1 person (or 3%) died who was between the ages of 21-30 years old
- 3 people (or 8%) died who were between the ages of 31-40 years old
- 5 people (or 14%) died who were between the ages of 41-50 years old
- 9 people (or 24%) died who were between the ages of 51-60 years old
- 9 people (or 24%) died who were between the ages of 61-70 years old

- 6 people (or 16%) died who were between the ages of 71-80 years old
- 4 people (or 11%) died who were between the ages of 81-90 years old

According to the National Center for the Health Statistics, people with intellectual and developmental disabilities of all ages have a life expectancy of 50.4 to 58.7 years compared to the general US population of 78.5 years (CDC 2011).

Place of Death:
- 20 people (or 54%) died in the hospital
- 13 people (or 35%) died at home
- 3 people (or 8%) died at a Long Term Acute Care (LTAC) facility
- 1 person (or 3%) died in another setting (parking lot)

Month of Death:
- 1 person (or 3%) died in the month of February 2016
- 2 people (or 5%) died in the month of March 2016
- 1 person (or 3%) died in the month of April 2016
- 3 people (or 8%) died in the month of May 2016
- 3 people (or 8%) died in the month of July 2016
- 3 person (or 8%) died in the month of August 2016
- 3 people (or 8%) died in the month of September 2016
- 4 people (or 11%) died in the month of October 2016
- 6 people (or 16%) died in the month of November 2016
- 4 people (or 11%) died in the month of December 2016
- 2 people (or 5%) died in the month of January 2017
- 5 people (or 14%) died in the month of February 2017

Residential Providers:
- 8 people (or 22%) died while living in their natural homes
- 1 person (or 3%) died while supported by Associate Community Service, Inc.
- 1 person (or 3%) died while supported by Anna Healthcare, Inc.
- 2 people (or 5%) died while supported by Bridge Point Nursing Home
- 3 people (or 10%) died while supported by Capital Care, Inc.
- 1 person (or 3%) died while supported by Frontline, Inc.
- 3 people (or 7%) died while supported by Innovative Life Solutions, Inc. (ILS)
- 2 people (or 5%) died while supported by the Lt. Joseph P. Kennedy Institute
- 1 person (or 3%) died while supported by Kensington Nursing Home
- 2 people (or 5%) died while supported by My Own Place, Inc. (MOP)
- 3 people (or 7%) died while supported by Multi-Therapeutic Services, Inc. (MTS)
- 1 person (or 3%) died while supported by RCM of Washington, Inc.
- 2 people (or 5%) died while supported by Vested Optimum Community Services
- 3 people (or 8%) died while supported by the Volunteers of America, Inc. (VOA)

- 3 People (or 8%) died while supported at the Wholistic Habitation Services, Inc.
- 1 person (or 3%) died while supported by Woods Services

Residential Setting Type:

- 13 people (or 35%) lived in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)
- 11 people (or 30%) lived in a Supported Living home
- 8 people (or 22%) lived in their natural home
- 2 people (or 5%) lived in a Residential Habilitation home
- 3 people (or 8%) lived in a Nursing Home

Length of Time Supported by their Most Recent DDS Support Coordinator (SC):

- 14 people (or 38%) had been supported by their most recent DDS Service Coordinator (“SC”) for one year or less
- 8 people (or 22%) had been supported by their most recent DDS SC for two years
- 4 people (or 11%) had been supported by their most recent DDS SC for three years
- 1 person (or 3%) had been supported by his most recent DDS SC for four years
- 4 people (or 11%) had been supported by their most recent DDS SC for five years
- 3 people (or 8%) had been supported by their most recent DDS SC for seven years
- 1 person (or 3%) had been supported by his most recent DDS SC for eight years
- 1 person (or 3%) had been supported by his most recent DDS SC for nine years
- 1 person (or 3%) had been supported by her most recent DDS SC for eleven years

DNR Orders:

- 17 people (or 46%) did not have a DNR/DNI order in place at the time of their death
- 20 people (or 54%) had a DNR/DNI order in place at the time of their death

Cause of Death Source:

- 20 people (or 55%) did not have an autopsy or external examination performed; however, death certificates were submitted for these deaths
- 13 people (or 34%) had an autopsy performed
- 4 people (or 11%) had an external examination performed

Expected/Unexpected Deaths:

- 20 people’s (or 53%) deaths were unexpected
- 17 people’s (or 47%) deaths were expected

An unexpected death is defined as a death that was not expected or anticipated as a result of any previously known medical diagnosis/condition or was a death that resulted from an accident. Of the 20 unexpected deaths, 10 deaths (or 50%) were determined to be

unpreventable; 7 deaths (or 35%) could not be determined if they were preventable or unpreventable; and 3 deaths (or 15%) were preventable.

Manner of Death:

- 35 people (or 95%) had their manner of death listed as natural
- 2 people (or 5%) had their manner of death listed as an accident

Preventable/Unpreventable Death:

- 24 (or 66%) of the deaths appeared not to be preventable
- 10 (or 26%) of the deaths could not be determined if it was preventable or not
- 3 (or 8%) of the deaths appeared to be preventable

The Determination of whether a death is preventable is often a complex question. After consultation with Columbus Organization physician reviewers, the following is being provided in answer to this question.

Each case is distinctive, and circumstances of each death are typically very specific and unique to that person. Columbus Organization physician reviewers determine whether a death is preventable or not preventable after a careful and thoughtful review of all the records they receive. Two criteria are usually needed for a death to be considered preventable:

- There was a clear deficiency in providing appropriate care or treatment to a person.
- There would have been a reasonable expectation that the person could have recovered/survived if appropriate care or treatment had been provided.
- The death was accidental in nature; if the accident had not occurred the person's death would have been preventable.

If these criteria are determined to be relevant in an individual case, then the determination that the person's death may have been preventable would be made. Outside of these parameters a death most likely would be considered not preventable.

Cause of Death:

- 13 people (or 35%) died from cardiac related causes
- 6 people (or 16%) died from aspiration pneumonia/pneumonia
- 4 people (or 11%) died from cancer
- 2 people (or 5%) died from respiratory related causes
- 2 people (or 5%) died from sepsis
- 2 People (or 5%) died from adult failure to thrive
- 1 person (or 3%) died from Alzheimer's disease
- 1 person (or 3%) died from complication of a fractured hip
- 1 person (or 3%) died from choking
- 1 person (or 3%) died from multiple injuries

- 1 person (or 3%) died from peritonitis
- 1 person (or 3%) died from complication of Protein S deficiency
- 1 person (or 3%) died from diabetic ketoacidosis
- 1 person (or 3%) died from propionic acidemia

Coexisting Diagnoses:

- 23 people (or 60.5%) had a diagnosis of hypercholesterolemia/ hyperlipidemia
- 22 people (or 58%) had mental health diagnoses
- 19 people (or 50%) had cardiac diagnoses
- 19 people (or 50%) had a diagnosis of hypertension
- 17 people (or 45%) had diagnosis of dysphagia
- 17 people (or 45%) had a diagnosis of a seizure disorder
- 16 people (or 42%) had a diagnosis of gastroesophageal reflux disease/ gastritis
- 14 people (or 37%) had a diagnosis of constipation
- 13 people (or 34%) had a diagnosis of anemia
- 13 people (or 34%) had a diagnosis of being overweight or obese
- 12 people (or 32%) had a gastrostomy tube
- 9 people (or 21%) had a diagnosis of Down syndrome
- 8 people (or 21%) had a diagnosis of Alzheimer's disease or dementia
- 7 people (or 19%) had a diagnosis of diabetes
- 4 people (or 11%) had a diagnosis of Autism
- 3 people (or 8%) had a diagnosis of chronic obstructive pulmonary disease

Individuals with intellectual disabilities often present with a variety of potentially complex co-morbidities (secondary health and behavioral conditions) that can elevate their relative mortality risk compared to the general population according to the Center for Developmental Disabilities Evaluation and Research. (DCCER)

B. Summary of Patterns/Trends

In summary, more people died:

- who were African-American (29 people or 78%) than were Caucasian (7 people or 19%) or Hispanic (1 person or 3%)
- who were male (28 people or 76%) than were female (9 people or 24%)
- between the ages of 51-70 (18 people or 49%) than any other age range
- in the hospital (20 people or 54%) than at home (13 people or 35%)
- in November 2016 (6 people or 16%) more than in any other month of fiscal year 2017
- while living in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IDD) (13 people or 35%)
- who were supported by their most recent DDS SC for one year or less (14 people or 38%)

- unexpectedly (20 people or 54%) than expectedly (17 people or 46%)
- whose deaths were not preventable (25 people or 68%)
- who had a DNR order (20 people or 54%) in place at the time of their death
- who did not have an autopsy performed (20 people or 54%) then did have an autopsy performed (14 people individuals or 37%)
- from cardiac related causes (13 people or 34%)

C. Other Findings

1. Most of the current published literature suggests that a person with Down syndrome has a life expectancy of 50 to 60 years according to Global Down Syndrome Organization. The ages at the time of death for nine people with Down syndrome who died during this review period were:
   - 1 person died at age 23
   - 1 person died at age 36
   - 1 person died at age 45
   - 1 person died at age 55
   - 1 person died at age 56
   - 1 person died at age 63
   - 1 person died at age 69
   - 1 person died at age 72
   - 1 person died at age 75

   During this reporting period, nine persons receiving services from DDS passed away from Down syndrome, six of the person lived beyond the expected age of 50. Four even lived past the age 60.

IV. Areas of Concern

The one major concern during this review period was the two accidental deaths. One person died of multiple injuries sustained after being struck by a truck, and another person died from complications following a right hip fracture. Both deaths may have been prevented if the correct staffing ratios would have been followed. In the case of the person being struck by the truck during a routine walk around the neighborhood. The decedent had cerebral palsy with congenital hemiplegia of the right hip and knee with arthritis, ataxia and unsteady gait pattern, he was reportedly wearing oversized and poor fitting orthopedic shoes that may have impaired his ability to safety ambulate, he had a documented low endurance and tolerance for walking per physical therapy assessment on December 23, 2016, and he was visually impaired. In addition, the decedent had a new rollator walker that he was using for the first time on date of the accident. With all the listed conditions, the provider should have had additional staff participate in the community walk. The provider had two scheduled staff on duty at the time of the accident. The person with hip

fracture has 2:1 staff support and fell out of bed and fractured her hip. It was determined in her final investigation report that the staffs were not trained in two-person pivot, use of the Hoyer life or in 1:1 or 2:1 staff supervision. The decedent's serious physical injury was substantiated for neglect.

The concerns found in the 37 mortality investigation report reviews, included, but are not limited to:

- Health Care Management Plans (HCMPs), Health Passports, and/or nursing assessments that were incomplete, inaccurate, or not up-to-date (19 people or 51%);
- Lack of recognition when a person has a change in condition, a life-threatening situation, and/or when to seek prompt medical attention (10 people or 27%);
- Lack of end-of-life planning (7 people or 19%);
- Medication indications not listed on the Medication Administration Records (MARs) or the physician orders and/or medication dosages not accurately listed on the MARs, Health Passport, and/or other pertinent records (3 people or 8%);
- Nursing assessments were not completed when the person had a significant change in condition and/or the assessment was not timely (3 people or 8%);
- Inaccurate date of birth documented (3 people or 8%); and
- Immunizations and healthcare screenings were not documented (3 people or 8%).

Recommendations

The following recommendations were made in two specific cases of the accidental deaths but are offered here again because of the significance this has regarding deaths that may have been prevented. In both cases, if the appropriate, adequate, and/or required staff supervision had been in place these deaths may have been prevented.

- Adequate staff supervision should be maintained at all times. In this case, the person "lagged behind the group" while taking their typical afternoon walk when he was struck by a truck.
- Staffing requirements should be appropriately maintained at all times. In this case, the person required 2:1 staff supervision but was left alone in her bedroom.

All of the following recommendations were specifically made in the individual mortality investigation reports completed. They are offered again in this summary report because of potential for systemic implications and/or statewide concern.

DDS should ensure that the DDS SCs assure that end-of-life planning is completed for all people supported or the rationale for not completing this planning is clearly documented.

DDS providers should ensure all staff are assessed and trained to appropriately respond to life-threating emergency events, including when to call 911 and initiate CPR. This should include the incorporation of quarterly CPR drills into their staff training.

DDS should continue to follow up with reviewing the guardianship training process to ensure that enhanced training is provided to guardians regarding quality of life issues, and timeliness of DNR implementation.

DDS community provider agencies should put in place, if not already in place, processes to ensure that:

- HCMPs and Health Passports are complete, accurate, and up-to-date;
- All support staff are adequately trained to recognize a change in a person's condition, a life-threatening situation, and when to seek prompt medical attention;
- End-of-life planning is completed for all people supported or the rationale for not completing this planning is clearly documented;
- All medication indications are listed on the MARS and the physician orders; and all medication dosages are accurately listed on the MARs, Health Passport, and/or other pertinent records;
- Nursing assessments are promptly completed when a person has a significant change in condition;
- That the person's date of birth is accurately listed on all of his/her records; and
- All of a person's immunizations and healthcare screenings are documented in the person's record.

IV Conclusion

By reviewing the information from each death, the MRC hopes to continue the initiation of the necessary changes to institute safer services for all individuals being served by DDS. An important outgrowth of this process is the recognition of best practices, and recommendations to implement those practices as systemic changes. The MRC understands that the information submitted for review cannot change the circumstances that led to the individual's death, however, this body strives to use the information that results from cases reviewed to identify trends, direct training needs, recommend development and/or modification of public agency and provider policies in order to address systemic issues and to improve the quality of life for these citizens of the District.

Acknowledgement

DDS would like to acknowledge the dedication and unwavering support of the public servants, private agency/program representatives, and community volunteers who serve as members on the Department on Disability Services Mortality 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 individuals we serve. 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.