GOVERNMENT OF THE DISTRICT OF COLUMBIA

DEPARTMENT ON DISABILITY SERVICES

DDS
Mortality Review Committee
Fiscal Year 2019
Report

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I. Introduction

This Mortality Review Committee 2019 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 **34** mortality investigation cases reviewed between October 1, 2018 and September 30, 2019. 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 to identify trends in the reports reviewed this fiscal year. The Mortality Review Committee meets at the Department on Disability Services in Washington, DC on the second Thursday of each month to review final investigations completed by a third party vendor that completes all death investigations. Columbus Organization is the third party vendor that has completed the investigation for all the cases in this report. Committee members are emailed final reports one week prior to the Mortality Review Committee meeting, which give them time to read the cases and develop recommendations to be discussed at the meeting. If a party is going to be absent from the meeting, they may forward their concerns and or recommendations to the DDS Mortality Review Coordinator who will share the concerns at the meeting. The committee will vote on if the concern rises to the level of a recommendation. The committee must vote and agree on all recommendations put forth. Recommendations can be assigned to DDS, DDS providers, or any other government agencies that played a role in the decedent's life. Once recommendations are developed and assigned, the DDS Mortality Review Coordinator emails the recommendations to the responsible party requesting a plan of correction. The recommendations are entered into DDS MCIS for tracking purposes. Recommendations are assigned an issue number which is unique to that recommendation. The plan of correction along with all supporting documentation are uploaded into MCIS and tracked to closure. DDS Mortality Review Coordinator reviews all plan of corrections with the providers to ensure all recommendations are being implemented as planned. All providers must have systems in place to address the recommendation and correcting the deficiency.

II. The Number of DC DDS Reviewed Mortality Cases:

Case Reviewed

There were a total of 34 mortality cases reviewed by the Mortality Review Committee between October 1, 2018 and September 30, 2019. Eighteen (18) of the 34 decedents were male. There was a significantly higher number of deaths among African-American (30) compared to Caucasians (4). 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 (2017). 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 19 was 46 years old.

III. Findings

A. Trends/Patterns

The following trends/patterns were found after reviewing the 38 mortality investigation reports for the above noted people.

Ethnicity:

- 30 people were African-American
- 4 people were Caucasian

During FY19, DDS supported 2,470 people. Of this number, 1,941 people were African-American, 128 people were Caucasian, 57 people were Latino, and 362 people were other races (Asian, Native American, unknown, or other). DDS recorded thirty-five deaths in the FY 19.

Sex:

- 18 people were male
- 16 were female

Age Range:

- 1 person died who was between the ages of 21-30 years old
- 2 people died who were between the ages of 31-40 years old
- 5 people died who were between the ages of 41-50 years old
- 9 people died who were between the ages of 51-60 years old
- 10 people died who were between the ages of 61-70 years old
- 5 people died who were between the ages of 71-80 years old
- 2 people 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:

- 25 people died in the hospital or in a Long Term Acute Care Facility
- 9 people died at home

Residential Providers:

- 3 people died while living in their natural homes

- 1 person died while supported by Associated Community Services, Inc.
- 3 people died while supported by BridgePoint LTAC
- 2 people died while supported by Community Multi-Services, Inc.
- 1 person died while supported by Finsby, Inc.
- 2 people died while supported by Future Care Pine View
- 2 people died while supported by Innovative Life Solutions, Inc. (ILS)
- 1 person died while supported by L'Arche Inc.
- 5 people died while supported by Metro Homes, Inc.
- 1 person died while supported by the Multi Therapeutic Services, Inc.
- 1 person died while supported by National Children Center, Inc. (NCC)
- 3 people died while supported by RCM of Washington, Inc.
- 1 person died while supported by Regency Nursing Home
- 2 people died while supported by St. Johns Community Services, Inc.
- 4 person died while supported by Volunteers of America, Inc.
- 2 people died while supported by Wholistic Habilitation Services, Inc.

Residential Setting Type:

- 13 people lived in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)
- 11 people lived in a Supported Living home
- 3 people lived in their natural home
- 6 people lived in a Nursing Home
- 1 people lived in a Host Home

Cause of Death Source:

- 24 people did not have an autopsy or external examination performed; however, death certificates were submitted for these deaths
- 10 people had an autopsy performed or an external examination performed.

Expected/Unexpected Deaths:

- 22 deaths were unexpected
- 12 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 a death that resulted from an accident.

Manner of Death:

- 31 people had their manner of death listed as natural
- 3 people had their manner of death listed as an accident

Preventable/Unpreventable Death:

- 26 of the deaths appeared not to be preventable
- 4 of the deaths appear to be preventable
- 4 of the death were listed as undetermined.

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:

- 1 person died from cardiac related causes
- 7 people died from aspiration pneumonia/pneumonia
- 3 people died from cancer
- 6 people died from respiratory related causes
- 5 people died from sepsis
- 1 person died from Alzheimer's disease
- 1 person died from choking
- 1 person died from multiple injuries
- 4 people died from complication of Down syndrome
- 4 people died from diabetic ketoacidosis

- 1 person died from Ogilvie syndrome

B. Summary of Patterns/Trends

In summary, more people died:

- who were African-American 27 people than were Caucasian 9 people
- who were male 22 were male to 16 who were female
- 13 people between the ages of 60-71 than any other age range
- 27 people in the hospital compared to 11 in their home
- while living in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IDD) (13 people)
- whose deaths were not preventable (32 people)
- who had an autopsy performed (17 people)
- from cardiac related causes (13 people)

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. Four final investigation report reviewed the decedent had a diagnosis of Down syndrome. Three of the decedents were older than sixty-two years old. I am sure medication and technology has a part in extending lives of person with Down syndrome, but this is the third year straight DDS has seen at least two people outlive the published literature on the life expectancy of a person living with Down syndrome.

IV. Areas of Concern

The Mortality Review Committee reviewed two case ruled preventable by Columbus Organization. One of the criteria Columbus Organization provides for a death considered preventable is the death was accidental in nature; if the accident had not occurred the person's death would have been preventable. One of the two cases reviewed involved a person that had a medical procedure which required sedation. She returned home and refused to exit her van so staff decided to allow her to remain on the van while they picked up her roommates from their day programs. In route to the first day program the decedent was allowed to eat her snack which was a peanut butter sandwich. Although the decedent had no history of choking, peanut butter is a well-known choking hazard and given that she was edentulous and had been sedated earlier that day, she was at a higher risk for choking. The death certificate listed the cause of death as

complication of gastric perforations due to nasogastric tube placement. Had the decedent not been given a peanut butter sandwich, she may have not needed EMS services to clear her airway after choking. Staff received training, and DDS issued an alert along with a transmittal guidance to the provider community agencies regarding food known to cause a greater risk of choking. The other case involved a person choking while waiting at her IDS pick up site. The decedent was able to get behind the counter of a donut shop and began to stuff donuts in her mouth before she collapsed. Staff intervened and called 911 and administered CPR. It was stated in the final report that the decedent did not have her appropriate 1:1 staff which is her staffing requirement in her home and day program. Her final report also raised the question if staff reacted to the choking episode correctly. Staff may not have recognized the signs of the decedent choking. According to the decedent's behavior support plan, grabbing food and other items she liked was one of her targeted behaviors. It was also noted in her final report, the decedent attempted to grab donuts a week before this time. According to one of her residential staff, one of the decedent's favorite food were donuts. Dunkin Donuts may not have been the best meeting place to begin her IDS. As a results of this case, all IDS meeting sites were evaluated to ensure they did not pose a risk to the person and were in line with their behavior support plans. Both providers involved changed and developed policies on drop off procedures. One change is when a provider drops off a person the provider cannot leave the person without the proper staffing person and or ratio. In this case the decedent would not have been dropped off if her one to one staff was not present. The residential staff would have remained with the decedent until the one to one staff arrived or would have taken the decedent back home for the day if the one to one staff was out of work. Both providers received intense monitoring from DDS Health and Wellness nurses and Quality Improvement Specialist.

The concerns found in the 34 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 (10 people)
- Lack of recognition when a person has a change in condition, a life-threatening situation, and/or when to seek prompt medical attention (1 person)
- Lack of end-of-life planning (8 people)
- 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 (6 people)
- Nursing assessments were not completed when the person had a significant change in condition and/or the assessment was not timely (15 people)
- Cases referred to the Department of Health including Maryland Department of Health (7)
- Behavior Support Plans not updated or not being followed. (7)

- Black box medication warnings. (1)

Recommendations

The Mortality Review Committee reviewed a total of 34 cases in FY 19 and developed or adopted one hundred seven nine recommendation (179) as a result of the committee's review. Eighty-four (84) of these recommendations were to the Department on Disability Services.

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 its Service Coordinator raise the topic of end of life or discussion at annual ISP meetings and document the results.

DDS should ask the FRC to review the case with the understanding that MRC has a concern about DC FEMS (Fire and Emergency Medical Service) stopping CPR and DC FEMS has not had an opportunity to respond to this concern; and that the MRC be updated with the results of that response and review.

DDS should revisit its regulations, policies, and procedures for in-home support providers to bolster the requirements of such agencies to have safeguards in place to ensure the health and wellness of people with ID/DD living in natural homes.

DDS should coordinate with Department of Health to encourage the development of protocols and procedures to address the systemic issue of hospice care agencies not ensuring that documentation of the plans of care are physically in the homes of people receiving outpatient hospice services.
DDS should review its Health and Wellness Standards and develop greater clarity on the use of the Health Passport in natural homes, including what constitutes appropriate DDS SC "assistance in its development and maintenance of current information" (See Health and Wellness Standard1)

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;
- Black Box listed medications are discussed with the PCP before administering
- Behavior Support Plans are updated, accurate and uploaded into MCIS.
- All clinicians are available to the investigation company to be interviewed about the decedent's care.

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.