2018 Preliminary Mortality Report

Commonwealth of Massachusetts
Executive Office of Health & Human Services
Department of Developmental Services

UMass Chan Medical School | Eunice Kennedy Shriver Center | Center for Developmental Disabilities Evaluation and Research (CDDER)

Prepared by the Center for Developmental Disabilities Evaluation and Research (CDDER) at the Eunice Kennedy Shriver Center, UMass Chan Medical School, with support from the Massachusetts Department of Developmental Services (DDS).

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Dear Colleagues and Friends:

The Department of Developmental Services' Preliminary Annual Mortality Report for 2018 is enclosed. This is an independent review of data on deaths occurring in 2018 for adults eligible for DDS supports. The Mortality Report is compiled by the Center for Developmental Disabilities Evaluation and Research (CDDER) of the UMass Chan Medical School.

The report analyzes information on all deaths occurring in calendar year 2018 for all persons 18 years of age or older who have been determined to be eligible for DDS supports. The report is a significant component of the Department's quality management system and reflects DDS's ongoing commitment to reviewing and learning from critical information gathered regarding individuals within our system. DDS is committed to a thoughtful and detailed review of deaths of individuals we support and the opportunity such a review presents for organizational learning. Massachusetts is one of a handful of states that compiles mortality information. We are proud of the fact that data from this report informs the Department's on-going service improvement efforts.

Annual Mortality Reports are reviewed by the Statewide Mortality Review Committee and the Statewide Quality Council and are a critical component of the Department's quality management and improvement system and an important step in our shared organizational learning process.

Sincerely yours,

Jane Ryder
Commissioner

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Executive Summary

This report presents population and mortality information about adults eligible for support from the Massachusetts Department of Developmental Services (DDS) between January 1 and December 31, 2018.

Annual mortality reports are part of Massachusetts DDS's robust quality management and improvement system. DDS's established processes for death reporting and mortality review provide the data included in this report.

Key points

- POPULATION – 28,678 adults were eligible for DDS services during 2018; of these adults, 490 died.
- RATE – Crude mortality rates have remained stable across years: 17.1 per thousand (2018); 17.5 per thousand (2017); and 16.4 per thousand (2016).
- AGE – Mortality rates were proportional with advancing age: for adults 75+ the mortality rate was 140.6 per thousand and for those aged 18-24 the rate was 2.0 per thousand. The average age at death of adults in the DDS population was 63.2 years
- GENDER – Male and female mortality rates were similar in 2018: 16.9 per thousand (female) and 17.2 per thousand (male).
- RESIDENTIAL SETTING – Mortality rates were lowest for adults living on their own or with family (6.4 per thousand) and those living in paid non-DDS settings (17.1 per thousand). Mortality rates were highest for people living in nursing homes (83.3 per thousand) and those living in DDS facilities (88.3 per thousand).

Overview

Patterns of mortality in the DDS population are influenced by several factors, including age, gender, and residential setting, as well as changes in eligibility for DDS services as mandated by law. In November 2014, eligibility was expanded to include people with certain developmental disabilities who experience multiple, substantial functional limitations. The impact of these factors is considered in this report.

This independent review was compiled by the University of Massachusetts Chan Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER). CDDER has written annual morality reports for DSS since 2000. The methodology used to collect, analyze, and present the information and data on the deaths of adults with intellectual and developmental disabilities eligible for DDS services is fully described in the appendix.

Mortality findings are used to inform quality improvement efforts for supports provided by DDS.

Introduction

This report presents population and mortality data for adults (18 years of age and older) eligible for services from the Massachusetts Department of Developmental Services (DDS). The mortality information in this report includes all adults who were eligible[1] to receive services in the Meditech Consumer System from January 1 to December 31, 2018 and who died during the 2018 calendar year.

The Massachusetts DDS utilizes a formal process for reviewing and reporting instances of mortality. This process, instituted in 1999, is an integral component of the Department's robust quality management and improvement system. Through this process, DDS reviews the causes and circumstances of the deaths of people DDS supports and uses the findings to inform quality improvement efforts of the Department. As part of this effort, the University of Massachusetts Chan Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER) has prepared annual reports on mortality of this population of Massachusetts citizens since 2000. To prepare each annual report, CDDER compiles mortality information from DDS records and from other external sources and performs the mortality and population analyses that are presented in this report.

DDS Clinical Mortality Review

Clinical mortality reviews are conducted by the DDS Mortality Review Committee for deaths of people served by DDS who:

- Were at least 18 years of age;
- Received a minimum of 15 hours of residential support provided, funded, arranged or certified by DDS;
- Died in a day support program funded or certified by DDS;
- Died in a day habilitation program; or
- Died during transportation funded or arranged by DDS.

Not all the people served by DDS who die meet the criteria for a clinical mortality review. See the section on mortality review for a more detailed description of the process. This report includes both deaths of people that received a clinical review, and those that did not.

This report is a preliminary analysis of mortality during 2018 that includes patterns of mortality across demographic factors (age, gender, and residential settings).

[1] See description of expanded eligibility for DDS services starting in November 2014 under the section entitled *People Served by DDS.*

People Served by DDS

With the passage of the 2014 Autism Omnibus Law in Massachusetts, important changes were made to the eligibility for DDS services for adults effective November 2014. This law expanded eligibility requirements to include adults with a developmental disability as defined in state law[2] as a severe, chronic disability that:

- presents as physical or mental impairment; and
- results from autism spectrum disorder, Prader-Willi Syndrome, or Smith-Magenis Syndrome with onset before age 22; and
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; capacity for independent living; economic self-sufficiency; and
- is likely to continue indefinitely.

Adults who are eligible for services under this expanded eligibility in 2018 are eligible for a narrower range of services than adults who are eligible due to an intellectual disability.[3] These changes to eligibility also alter the range of decedents that may be included in annual DDS analyses starting in 2015.

Since the population served by DDS fluctuates over the course of the year, the midyear population is used as an estimate of the annual population in this report. In the middle of calendar year 2018, the Massachusetts DDS served 28,678 adults (18 years of age and older) with intellectual and developmental disabilities. A net increase of 4%, or 1,095 people, was seen in the mid-year adult consumer population from June 2017 to June 2018.[4] Appendix B provides additional details about the annual population changes.

Overall, the population served by DDS tends to be younger than the general population, with a smaller proportion of people living into older age groups (e.g., 65 years and older). Well over half of the DDS population live in their own home independently or with family (58%), approximately one-third (35%) live in community-based supported residential settings, and the remainder (7%) live in other settings including nursing homes, DDS facilities, and other staff-supported locations. See Appendix B for more details on age, gender, and residential setting distributions.

[2] Chapter 226 of the Acts of 2014, *An Act Relative to Assisting Individuals with Autism and Other Intellectual or Developmental Disabilities*.

[3] Community Developmental Disability Services available under expanded eligibility include: employment/day services; individual supports to assist individuals who may be living more independently; support services for assistance both in-home and in the community (e.g., adult companion, individualized home supports, behavioral supports and consultation, and peer support); and family support services for individuals living with their families, including respite, family training, and flexible funding. Support models with 24-hour staffing were typically not available in 2018.

[4] Total DDS Population on July 1, 2018 was 28,678 and on July 1, 2017 was 27,583, a net increase of 1,095 people.

Mortality Statistics

In 2018, a total of **490 deaths** occurred for people eligible for DDS services, for a crude mortality rate of **17.1 deaths per thousand people**.[5] The average age at death was 63.2 and the median[6] age at death of adults in the DDS population was 64.4 in 2018. Appendix A describes the methodology used to collect and analyze the information and data contained in this section.

Table 1 shows the number of deaths, mortality rates and average age at death for the DDS population for 2009 through 2018. While the number of deaths reached a new high in 2018, the population served also hit a new high, resulting in a mortality rate in 2018 that was consistent with the mean mortality rate over the last nine years. Likewise, the year to year change in mortality rate, 2017 to 2018, was not significantly different.[7]

The average age at death was 63.2 years in 2018, a non-significant difference from the average age at death of 62.5 years in 2017.[8]

Table 1: *Mortality Trends in DDS Population, 2009-18*

Year	Number of Deaths	Mortality Rate (per 1000)	Average Age at Death (in years)
2009	421	17.6	58.7
2010	406	16.6	61.5
2011	440	18.4	61.1
2012	438	19.2	62.5
2013	409	17.4	61.1
2014	412	16.6	60.9
2015	463	18.0	63.1
2016	431	16.4	61.4
2017	482	17.5	62.5
2018	490	17.1	63.2

Age

Mortality statistics for the adult population are presented by age group in Table 2. The use of a mortality rate (deaths per thousand people) controls for differences in the population between age groups and allows for age groups of different size to be compared to each other.

Table 2: *Distribution Deaths by Age Group, 2018*

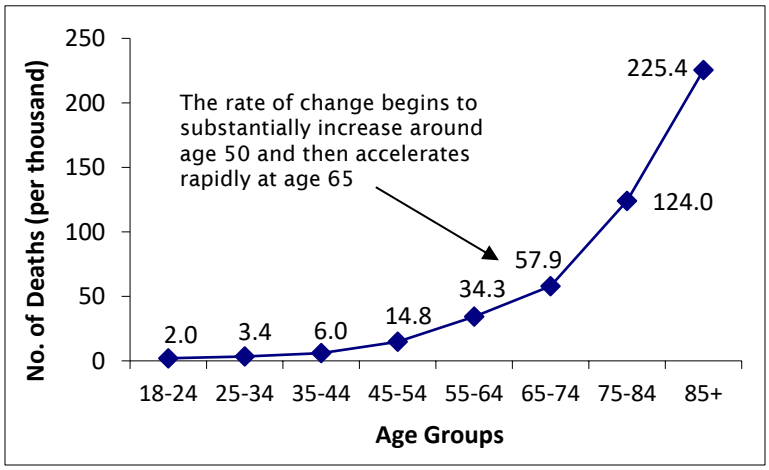
Age Range	Number of Deaths	Percent of Deaths	Mortality Rate (per 1000)
18-24	14	2.9%	2.0
25-34	23	4.7%	3.4
35-44	24	4.9%	6.0
45-54	60	12.2%	14.8
55-64	132	26.9%	34.3
65-74	115	23.5%	57.9
75-84	90	18.4%	124.0
85+	32	6.5%	225.4
TOTAL	**490**	**100%**	**17.1**

[5] Standard recommended by the U.S. Centers for Disease Control and Prevention, National Vital Statistics Report, *Age Standardization of Death Rates: Implementation of the Year 2000 Standard*, Vol. 47, No. 3, 1998.
[6] Median = the mid-point age if all deaths were ordered from youngest age to oldest age.
[7] To test for a difference in mortality rates between 2018 and 2017, a chi square test was used. No significant difference in mortality rates between 2018 and 2017 was found ($\chi^2 = .12$, d.f. = 1, p-value = .73).
[8] A z-test for means was conducted comparing the average age at death in 2018 (M=63.2, SD=16.2) to the average age at death in 2017 (M=62.5, SD=16.4). No significant difference in the average age at death in 2018 and in 2017 was detected (z test = -.69, p-value = .49, two-tailed).

The relationship between age and rate of death for adults served by DDS is displayed in Figure 1. The line in Figure 1 illustrates the increase of mortality rate with age. In the older age groups (age 65+) mortality rates are the highest, showing sharp increases compared to younger age groups. These higher rates reflect the expected increase in risk of mortality for adults of advanced age. A very similar pattern between rate of death and age was seen in previous years.

The mortality rate is calculated by dividing the number of deaths by the total DDS population in 2018 and multiplying by 1000.

Figure 1: *Mortality Rate by Age Group, 2018*



Gender

Gender proportions vary with age in the DDS population, and a complex relationship exists between gender and mortality. Table 3 displays the adult population, number of deaths, percent of overall deaths, average age at death and rate of death for each gender. The adult mortality rate for females was 16.9 per thousand in 2018 (compared to 18.3 per thousand in 2017). For males, the adult mortality rate was 17.2 per thousand in 2018 (compared to 16.9 per thousand in 2017).

Table 3: *Average Age at Death and Mortality Rate by Gender, 2018*

Gender	DDS Population	No. Deaths	Percent of Deaths	Average Age at Death	Mortality Rate (n/1000)
Female	11,683	198	40%	64.5	16.9
Male	16,994	292	60%	62.4	17.2
Unreported	1	0	-	-	-
Total	**28,678**	**490**	**100%**	**63.2**	**17.1**

Residence

Adults eligible for DDS services live in one of five general types of residential settings:

1. their own home either independently or with family;
2. community settings operated, funded, or certified by DDS;
3. residential programs that are not part of the DDS system;
4. facilities operated by DDS; and
5. nursing homes or other long-term care settings.

Mortality statistics for these residential categories are displayed in Table 4.

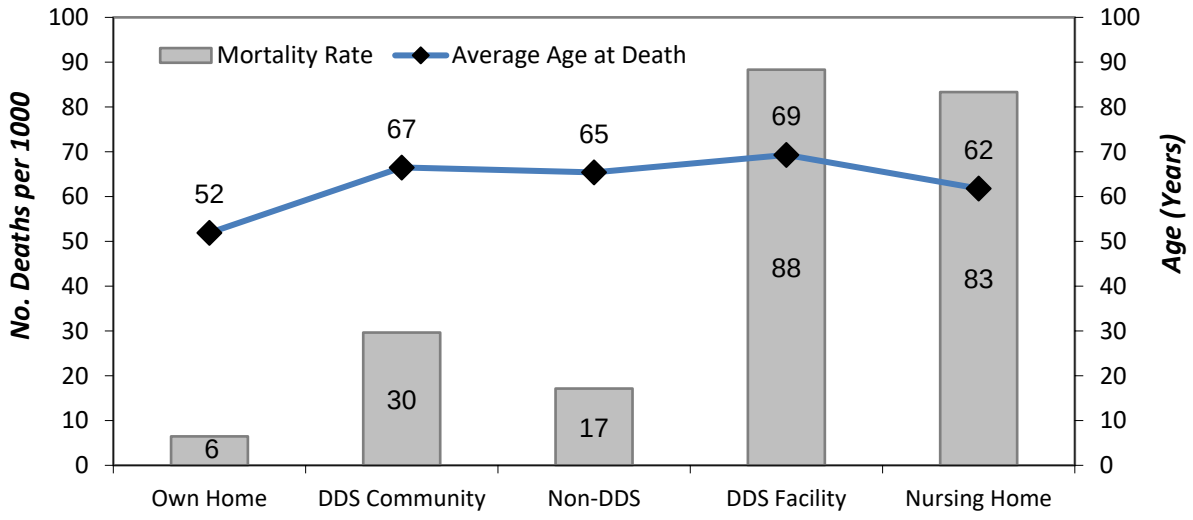
Table 4: *Age and Mortality by Type of Residence, 2018*

Residential Setting	DDS population[9]	% of DDS population	% of DDS population ≥65 years	No. Deaths	Percent of Deaths	Average Age at Death	Mortality Rate (n/1000)
Own Home	16,912	58%	4%	109	22%	51.9	6.4
DDS Community	10,259	35%	19%	304	62%	66.5	29.6
Non-DDS	1,633	6%	14%	28	6%	65.4	17.1
DDS Facility	385	1%	46%	34	7%	69.3	88.3
Nursing Home	180	1%	20%	15	3%	61.8	83.8
TOTAL	**29,369**	**100%**	**10%**	**490**	**100%**		**17.1**
Average						**63.2**	

Age and Residence

The average age at death varies across residential settings. Generally, the average age at death for each residential setting is reflective of the relative age and the health status of the population that resides in each setting. Generally, in the DDS population, the rate of death has been higher in residential settings which have a higher average age at death. This is an expected finding since age is highly correlated with risk of mortality.

Figure 2: *Mortality Rate and Average Age at Death by Type of Residence, 2018*



[9] Summing the DDS population by residential setting (i.e., the DDS population column) results in a higher count than the actual DDS population count shown on the table. This is due to duplications in enrollment data. A person may be classified in more than one residential setting. The duplication is small, a difference of +691 people out of 28,678 or 2.4% of the total DDS population. The Total Mortality Rate in Table 4 is calculated using the actual DDS population rather than the total residential setting population given that duplication.

The average age of death across all care settings in 2018 was comparable to 2017. As shown in Table 4 and Figure 2, the average age at death was lowest for people living in their own home (52.0 years) and highest for those living in DDS Facilities (69.6 years) and DDS Community settings (66.5 years). This is an expected pattern because the average age of adults served by DDS who reside in their own home is usually younger than those who reside in DDS Facilities or nursing homes. In addition, ongoing efforts in recent years to move people living in DDS Facilities and nursing homes to community-based settings has resulted in a smaller, older population of people living in these settings.

Own Home

People served by DDS living independently in their own home or with family comprised over half of the individuals served by DDS in 2018 (58%), an increase from previous years. Most services provided to people eligible for DDS services under the expanded eligibility starting in November 2014 are people in this setting.

This subgroup had the lowest mortality rate in 2018. The crude adult rate of death for those living in their own home was 6.4 per thousand in 2018, which was slightly lower than last year but not significantly different.[10] The subgroup of people living in their own homes is the youngest on average of all residential subgroups and has the smallest percentage of people over the age of 65 (4% in 2018). This is reflected in the relatively low average age at death of 51.9 years. The crude adult mortality rates for people living in their own home (6.4 per thousand) is slightly lower than the crude mortality rate of 6.8 per thousand in 2018 for all ages of the general population of Massachusetts.[11]

DDS Community

DDS Community describes a diverse residential subgroup both in terms of age and level of service need. This is the second-largest residential subpopulation of adults receiving DDS services in Massachusetts and comprises more than one-third of the DDS population. The crude adult mortality rate for people served by DDS living in the DDS Community was 29.6 per thousand in 2018, which is not significantly different from 2017 data.[12] The average age at death (66.5) is similar to the average age for this population. As people with high medical needs who were previously living in nursing homes and DDS facilities are transitioned out of these settings and largely into DDS community settings, the mortality rate can be expected to increase slightly over time.

Other Residential Settings

The remaining three residential settings, Non-DDS funded supported settings, DDS facilities and nursing homes, represent approximately 8% of the entire DDS population. It is important to note that such small

[10] The proportion of deaths to the DDS population for the subgroup of those living independently (Own Home) for 2018 was compared to 2017 using a z-test for proportions. No statistical difference was detected between 2018 and 2017, z = -.27, p = .78, two tailed.

[11] *Massachusetts Deaths 2018.* Office of Data Management and Outcomes Assessment, Massachusetts Department of Public Health, October 2019. Table 1: Trends in Mortality Characteristics, Massachusetts: 2007 – 2018. https://www.mass.gov/doc/2018-death-report/download.

[12] The proportion of deaths to the DDS population for the subgroup of those living in the DDS Community for 2018 was compared to 2017 using a z-test for proportions. No statistical difference was detected between 2018 and 2017, z = -.61, p = .54, two tailed.

population numbers can result in large annual fluctuations in the rate of death when compared by residential setting. Changes in rate should therefore be interpreted with caution as small changes will have a relatively large impact on mortality rates.

Non-DDS

The Non-DDS category includes a variety of residential settings, some of which are paid for by other Health and Human Services Agencies as well as some special programs. These settings include inpatient facilities run by other state agencies, Adult Foster Care settings, homeless shelters, and assisted living settings. Because of this, demographics among this group tend to vary greatly, which contributes to annual fluctuations in mortality patterns within this setting. In 2018, 28 people served by DDS living in Non-DDS residence settings died. The adult mortality rate for this subgroup was 17.1 per thousand in 2018, which was not significantly higher than the 2017 rate (15.7 per thousand) for the Non-DDS residence setting. [13]

DDS Facilities

The proportion of the population in this setting continues to shrink as efforts are made to shift facility-based residential supports to community-based supports. Between 2017 and 2018, the percentage of the DDS population residing in DDS Facilities was unchanged, 1% (2017) and 1% (2018). The population remaining in facilities is the oldest of all residential settings, with approximately 46% over the age of 65. In 2018, 34 people died for a crude adult mortality rate of 88.3 per thousand, the highest rate of death of all residential settings. Still, the mortality rates in 2018 and 2017 for this setting were not significantly different.[14] Because of the changes to the underlying population in this setting, comparisons between years should be made with caution.

Nursing Homes

Since the Supreme Court's *Olmstead vs. L.C.* (1999) decision, states are required to screen all applicants to a Medicaid-certified nursing facility for intellectual disabilities to help ensure that people receive the assistance they require in the least restrictive setting and are not inappropriately placed in nursing facilities.[15] As a result, people living in this setting have some of the highest care needs of all people served by DDS and 20% are over the age of 65 years. The population of people served by DDS living in nursing homes is the smallest population overall and represents less than 1% of all individuals served. In 2018, 15 people who were residing in nursing homes (for more than 30 days) died. This setting had a crude adult mortality rate of 83.3 per thousand in 2018, representing the second highest rate of death of all residential settings after DDS Facilities. No significant difference was observed between 2017 and 2018 in the mortality rate for people residing in nursing homes.[16] The mortality rate for this setting is likely affected by increased efforts to divert people from living in nursing homes when possible, resulting

[13] The proportion of deaths to the DDS population for the subgroup of those living in the non-DDS settings for 2018 was compared to 2017 using a z-test for proportions. No statistical difference was detected between 2018 and 2017, $z = .34$, $p = .74$, two tailed.

[14] A z-test of the proportions of deaths to population for the subgroup of those living in DDS Facilities in 2018 compared to 2017 was conducted. No statistical difference was found between 2018 and 2017, $z = 1.88$, $p = .06$, two-tailed.

[15] https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Preadmission-Screening-and-Resident-Review-PASRR.html.

[16] The proportion of deaths to the DDS population for the subgroup of those living in Nursing Homes for 2018 was compared to 2017 using a z-test for proportions. No statistical difference was detected between 2018 and 2017, $z = .92$, $p = .36$, two tailed.

in a greater proportion of people in these settings being at the end of their lives. Deaths in this setting represented 3% of all deaths for people served by DDS.

Hospice

In 2018, 44% of deceased individuals received hospice support or 218 people out of 490. This proportion was slightly higher compared to the proportion who received hospice support in 2017 (see Table 5 below). Historically, the rate of hospice use for DDS decedents tends to be similar to the rate of hospice use for the general population. The proportion of Medicare decedents served by hospice was 51% in 2018, the most recently available data.[17]

Table 5: *Number of Individuals Receiving Hospice Support, 2017-2018*

	2017		2018	
Hospice	**No. Deaths**	**Percent of Deaths**	**No. Deaths**	**Percent of Deaths**
Yes	203	42%	218	44%
No	250	52%	247	50%
Unknown	29	6%	25	5%
TOTAL	**482**	**100%**	**490**	**100%**

Mortality Review Process

Clinical mortality reviews are completed by DDS for all deaths involving people who meet the following criteria:

1. 18-yrs of age and older,
2. receive a minimum of 15-hours of residential support provided, funded, arranged, or certified by DDS, or
3. died in a day support program funded or certified by DDS, or
4. died while participating in a day habilitation program, or
5. died during transportation funded or arranged by DDS.

Mortality reviews for this population are either required, based on the criteria above, or requested. Required mortality reviews are submitted to the Regional and/or Central Review Committee for analysis, for confirmation of the cause of death, and for follow-up if it is indicated. In 2018, 335 mortality reviews were required according to these criteria for deaths occurring in calendar year 2018. Of the 335 required reviews, 327 were completed for a completion rate of 98%. Seven (7) additional mortality reviews were requested in 2018, and all 7 were completed. For comparison, in 2017, 337 mortality reviews were required with 321 reviews completed, yielding a completion rate of 95% for 2017.

[17] As reported in the National Hospice and Palliative Care Organization Facts and Figures: Hospice Care in America report 2020 Edition which cite the 2018 NHPCO National Data Set, https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf.

DDS Central Office conducts follow-up activities to correct process issues related to missed reviews and ensure they are completed.

Mortality Review Procedure

Mortality review overall includes a multi-tiered approach. A Clinical Mortality Review is conducted by the DDS Area Nurse or Facility Nurse utilizing the standardized Clinical Mortality Review Form. Clinical Mortality Review Forms are submitted, reviewed and signed by the Regional Director, Facility Director, or their designee within 30 days of the death. Completed reviews are recorded and submitted electronically where they are accessed by Central Office along with any supporting information such as the death report.

A review of each case is conducted by the **Regional Mortality Review Committee** which consists of at least one Registered Nurse and one Risk Manager, and other members as assigned at the discretion of the Region. When reviewing a case, the Regional Committee considers if there are any unanswered questions with respect to timely diagnosis or identification of health issues, appropriate treatment or intervention, standards of care, advocacy, staff training, medication regimen, or clinical oversight. The Regional Committee seeks answers to any questions raised in the review process before determining if the case can be closed or must be referred to the Central Mortality Review Committee based on a list of criteria provided.

The **Central Mortality Review Committee** is made up of the DDS Director of Health Services, DDS Director of Risk Management, DDS Director of Investigations, representatives from Regional Mortality Review Committees, one physician, and the Disabled Person's Protection Commission, a clinical pharmacist, a DDS nurse practitioner, and a DDS ethicist. Cases referred to the Central Mortality Review Committee are reviewed, and a final cause of death is verified. Additional information may be sought and following this, cases are closed as appropriate.

A random review of at least 10% of the cases closed at the regional level is conducted annually by the Central Committee to determine whether cases are being closed appropriately and to identify any new criteria for referral to the Central Committee.

Investigations

All death reports received by DDS are reported to the DDS Investigations Division, which ensures that deaths are also reported to the Disabled Persons Protection Commission (DPPC) where appropriate. Whenever there is a suspicion that the death of a person with an intellectual or developmental disability was the result of abuse, neglect or omission, the Disabled Persons Protection Commission (DPPC), and/or the DDS Investigations Division, and/or the Department of Public Health (DPH) investigates the causes, manner, and circumstances of the death. Also subject to investigation are any deaths that meet medico-legal requirements in the Massachusetts General Laws, chapters six and thirty-eight.[18]

[18] "Any death in which the Chief Medical Examiner takes responsibility for determining the cause and manner of death, to include all cases of suspected homicide, suicide, accidental drug overdose, or sudden and unexpected natural deaths."

Some deaths may involve more than one investigation by more than one state agency. For example, DPH is charged with investigating allegations of abuse, mistreatment or neglect in certain licensed health facilities including hospitals, rehabilitation hospitals and nursing facilities. Therefore, DPPC or DDS may conduct an investigation of issues in a DDS funded or licensed setting and DPH may conduct a separate, non-duplicative investigation of the care the person received while in an acute care hospital.

Table 6 displays investigation information for 2009–2018. The number of deaths investigated in 2018 was lower than the number of deaths investigated in 2017 (17 investigated deaths in 2018 versus 27 in 2017). Still, the number of deaths investigated in 2018 remained in line with numbers of deaths investigated since 2009, except for 2014, which had an unusually low number of investigations. In 2018, DDS conducted seven (7) investigations and DPPC conducted three (3) investigations. Law enforcement reviewed three (3) cases in 2018.

Table 6: *Summary of Investigations, 2009-2018*

Type of Activity	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
DDS Investigation	13	5	3	10	9	6	10	16	14	7
DPPC Investigation	3	3	1	3	3	2	2	1	2	3
Refer to Other Agency	3	4	4	2	6	0	2	2	3	1
District Attorney/ Law Enforcement Investigation	3	10	12	13	9	5	4	1	4	3
Other/dismissed[19]	2	3	2	4	2	2	5	3	3	2
Resolved Fairly & Efficiently	1	1	0	1	0	0	0	0	0	0
Direct to Complaint Resolution Team (CRT)	-	-	-	-	-	-	-	-	1	1
Total Deaths Investigated	**25**	**26**	**24**	**20**	**21**	**10**	**23**	**23**	**27**	**17**

Table 7 presents the findings of investigations by either DDS or DPPC. Investigations regarding six (6) of the deaths that occurred in 2018 found the allegations substantiated, meaning the death was the result of abuse, neglect, or omission. Seven (7) allegations in 2018 were found to be unsubstantiated. The remaining four (4) cases were either dismissed, referred for administrative review, or referred to other agencies. No case is pending.

Table 7: *Findings in Cases Investigated by DDS or DPPC, 2009-2018*

Findings	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
Substantiated	3	5	4	5	3	2	6	6	8	6
Pending	1	1	2	0	1	0	0	0	1	0

(NOTE: Includes cases deferred to law enforcement)

[19] Complaint was Dismissed, Resolved without Investigation, or Referred to the Regional Office for administrative review.

Appendix A

METHODOLOGY FOR MORTALITY REVIEW AND ANALYSIS

This mortality report analyzes information on all deaths occurring in calendar year 2018 for all people with intellectual and developmental disabilities, 18 years of age or older, who have been determined to be eligible for DDS supports (including expanded eligibility starting in Nov 2014).

The source data for this report comes from DDS Death Records that must be completed within 24 hours of a person's death according to DDS policy. This report includes statistics on all deaths of people who died in calendar year 2018 and whose Death Report was received by DDS by the writing of this report.

The data used to calculate death rates per 1000 by age group and type of residence was supplied by the DDS Meditech System of July 1, 2018.[20] The Meditech system contains information on every person eligible for DDS supports, including those who may not be receiving DDS services currently.

DDS provided the following information for deaths:

- Name of the person
- Date of birth
- Date of death
- Social security number
- Cause of death, if known
- Residence type
- DDS region
- Whether death was referred for investigation
- Whether a Mortality Review form was received

Crude mortality rates were calculated for the entire DDS population. Death rates were also calculated by age category, region, and residence type. The specific methodology employed by CDDER for calculating death rates per 1000 for each of the categories is as follows:

$$\text{Crude Death Rate} = \frac{\text{(Number of people who died in calendar year x 1000)}}{\text{(No. of people in Meditech systems in middle of calendar year)}}$$

[20] CDDER relies on the accuracy of information about the number of people eligible for DDS services, their ages, region, and type of residential placement. Inaccuracies in DDS information systems, if any, will be reflected in the numbers used to compute death rates in the DDS population.

Appendix B

DEMOGRAPHIC DATA

Age Characteristics

Table 8 and Figure 3 presents the age distribution for the DDS population in 2018. With the exception of population groups under age 25 and over age 84, populations are in 10-year age groups. The largest populations are in age bands between 18 and 24, and 25-34, with over 7,100 and 6,800 respectively. Most age bands experienced a 6% or less fluctuation between 2017 and 2018, except for the youngest age band. The age group of 18-24 years experienced an 8% increase, and the 25-34 age group a 6% increase (see Figure 4 and Table 9). Compared to the Massachusetts general adult population, a greater proportion of adults served by MA DDS are under age 65 (90% compared to 84%).[21] Also, while only 0.5% of the MA DDS population is age 85 or older, 2.7% of the Massachusetts general adult population is within this age group.

Table 8: *Population Served by DDS by Age Group and Gender, 2018*

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	2,331	2,709	1,730	1,774	1,729	967	366	77	11,683
Male	4,795	4,112	2,246	2,279	2,118	1,019	360	65	16,994
Unreported	1	0	0	0	0	0	0	0	1
Total	**7,127**	**6,821**	**3,976**	**4,053**	**3,847**	**1,986**	**726**	**142**	**28,678**

[21] Annual Estimates of the Resident Population for Selected Age Groups by Sex for Massachusetts, American Community Survey (ACS 1-Year Estimates Subject Tables), S0101 Age and Sex for 2018. U.S. Census Bureau: https://data.census.gov/cedsci/table?q=massachusetts%20population%20in%202018%20by%20age&tid=ACSST1Y2018.S0101 (accessed 8-29-2022).

Figure 3: *Population Served by DDS by Age Group and Gender, 2018*

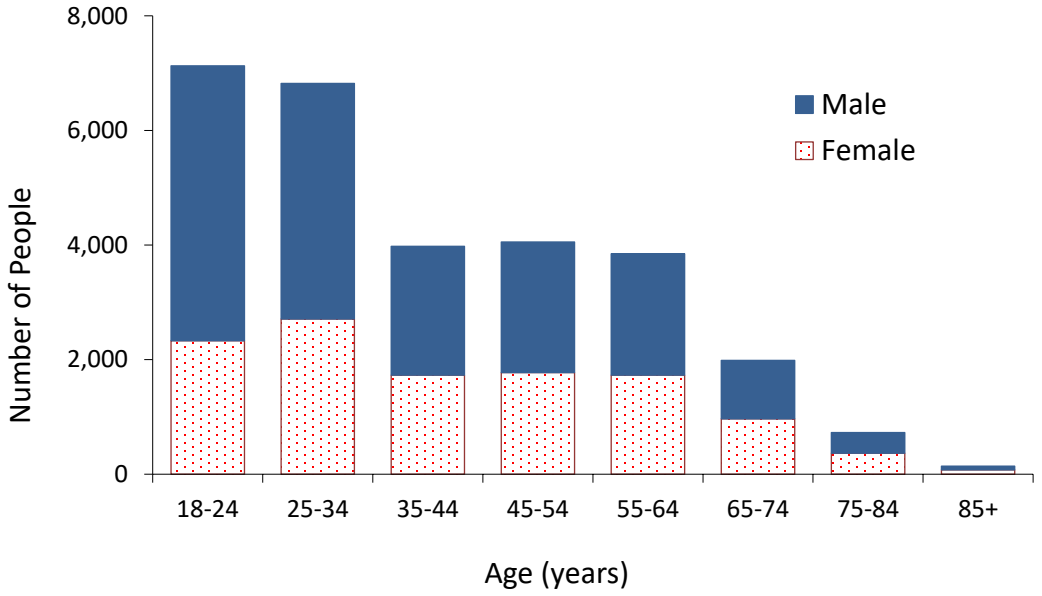


Figure 4 presents the change in the DDS population between calendar years 2018 and 2017. Between 2018 and 2017, there were more people served in the younger age groups – 18-24 years, 25-34 years, and 35-44 years – with the largest gain in the 18-24 age group.

Figure 4: *Population Served by DDS, Change in Number and by Percent, 2017-2018*

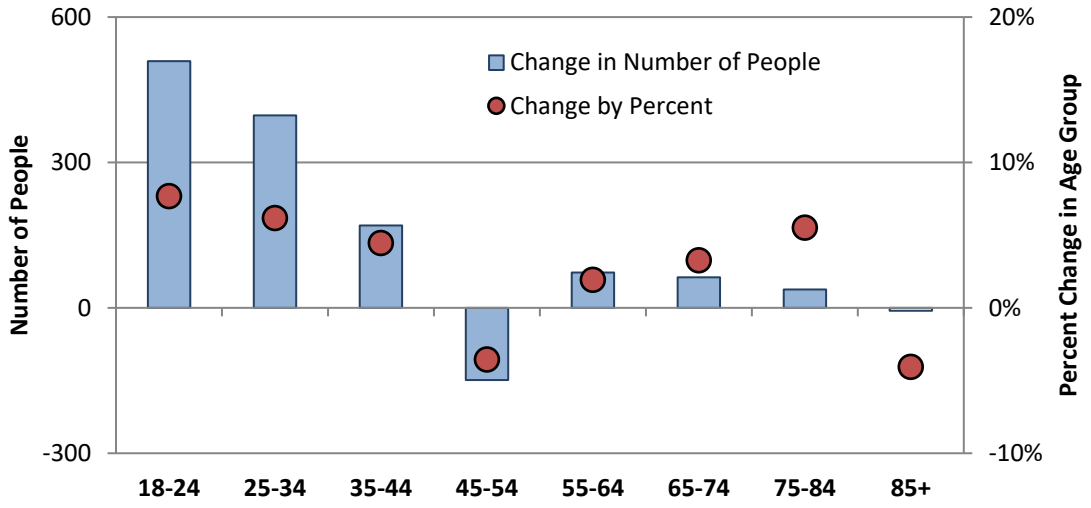
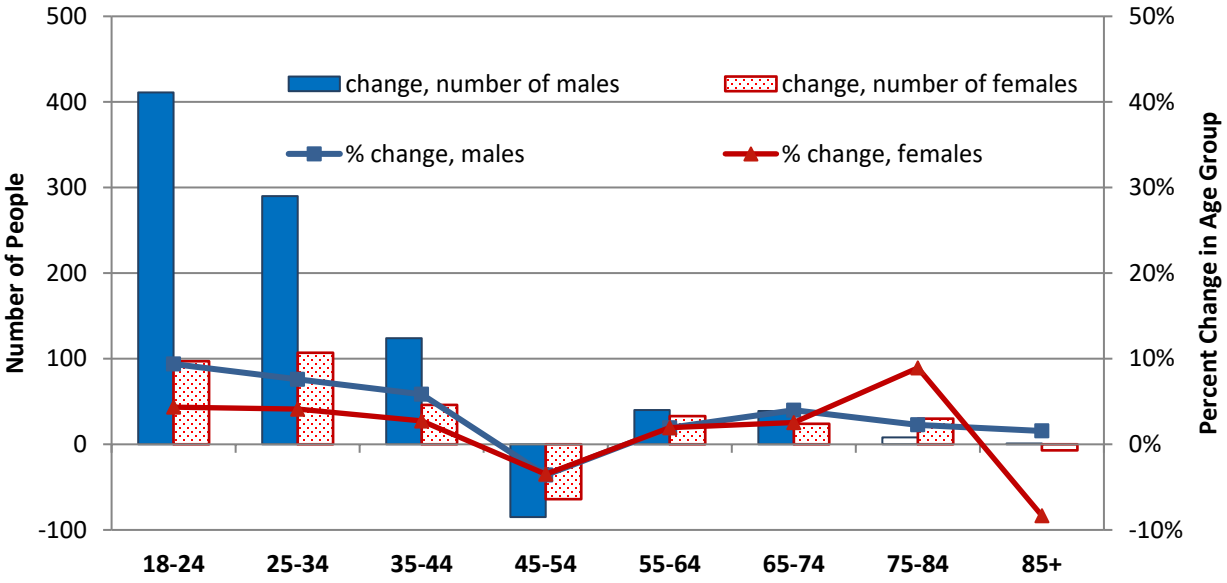


Figure 5 illustrates that DDS population patterns differed by gender with large proportional increases in the male population in 2018 at both the 18-24 age group and 25-34 age group.

Figure 5: *Population Served by DDS, Change by Gender, 2017-2018*



As shown in Figure 5 and in Table 9, and comparable to 2017, most young adults coming into adult services are males. More than twice as many males as females comprised the 18-24 year age group in 2018 (4,795 males aged 18-24 versus 2,331 females aged 18-24). Additionally, the increase of the 18-24 age cohort (509 people out of 1,095 people across all age cohorts) was responsible for most of the increase (4%) in the DDS population from 2017 to 2018.

Table 9: *Population Served by DDS, Change by Age Group, 2017 to 2018*[22]

Age Group	Net Change in Population	% Change in Population within Age Group	Resulting % Change in DDS Population from 2017
18-24	509	7.7%	1.8%
25-34	397	6.2%	1.4%
35-44	170	4.5%	0.6%
45-54	-149	-3.5%	-0.5%
55-64	73	1.9%	0.3%
65-74	63	3.3%	0.2%
75-84	38	5.5%	0.1%
85+	-6	-4.1%	0.0%
Total	**1,095**	**4.0%**	**4.0%**

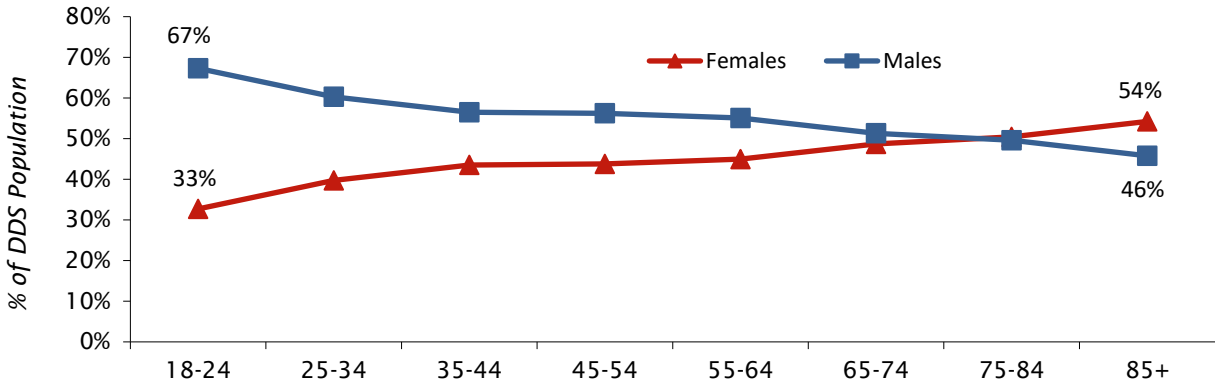
[22] Gross population change reflects the migration of living people between age groups. The figures in Table 9 take into account the people that must have entered the age group to compensate for deaths over the course of the year. The percent increase in the population will not match the net population increase.

This demographic change is largely in line with what was observed in 2017. In fact, females outnumber males in only the two oldest age groups: the 75-84 year old cohort (in 2018, 366 were female and 360 were male) and the cohort comprised of people aged 85 and above (in 2018, 77 were female and 65 were male). Overall, the total DDS population was slightly younger in 2018 compared with 2017. One in four persons receiving services from DDS were from the youngest age group, 18-24 years old, or put another way, 25% of the 2018 DDS population was from the 18-24 age cohort versus 24% of the DDS population in 2017.

Gender Characteristics

The gender distribution in the 2018 adult DDS population resembles previous years. The proportion of men served by DDS is highest for individuals aged 18-24 and decreases by age group, as shown in Figure 6. The proportion of men is higher for all adult age groups except for older adults over the age of 85. The shift in gender distributions in the elderly population is similar to what other states report seeing in the general population.

Figure 6: *Gender Distribution by Age, 2018*



Residential Setting Characteristics

Adults receiving services from DDS reside in a variety of different settings. In this report, the residential settings are grouped into five categories: persons residing in their own home, either independently or with family; community settings operated, funded, or certified by DDS; residential programs that are not part of the DDS system; facilities operated by DDS; and nursing homes or other long-term care settings. The percent of people served by DDS living in each residential category is presented in Figure 7.

In 2018, 57.6% of the adults served by DDS resided in their own home, which includes people living independently or with their family. This is up slightly from the percentage of people living independently or with their family in 2017, which was 55.7%.

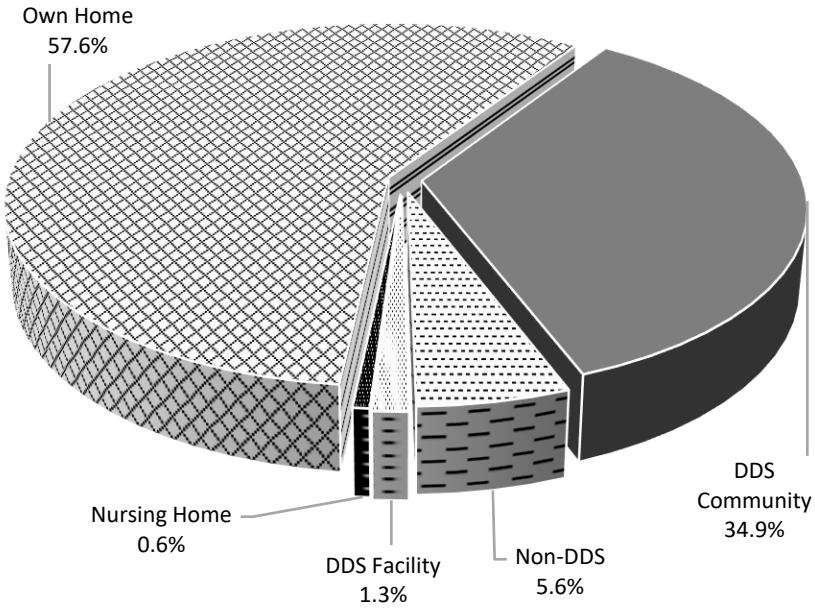
Residential programs operated, licensed/certified or funded by DDS make up the second most common residential setting as seen in the dark grey sections in Figure 7. In 2018, about 34.9% of adults served by DDS lived in a community residential program.

The number of people living in DDS facilities continues to slowly decline annually. In 2018, 1.3% of the DDS population lived in DDS facilities compared to 1.3% in 2017. The decline is largely due to DDS's efforts to plan transitions to community settings for these residents. Several initiatives in Massachusetts have contributed to the declining number of individuals served by DDS residing in facility-based settings. These include the Rolland vs. Patrick lawsuit, which was dismissed in 2013 after 640 class members transitioned out of facilities,[23] the closure of several DDS Residential Care facilities, and the Money Follows the Person Demonstration. All of these initiatives align with the Massachusetts Community First Olmstead Plan, which includes as one of its goals to "help individuals transition from institutional care."[24]

In 2018, about 6.2% of adults served by DDS resided either in programs that are funded privately or by other agencies or in nursing homes. In 2017, this portion was 6.9% of the DDS population. The portion of the population living in the Non-DDS setting (light grey with dashes in Figure 7) fell half of percentage point, from 6.1% in 2017 to 5.6% of the population in 2018. The proportion of the DDS population residing in nursing home also declined, from 0.8% in 2017 to 0.6% in 2018.

Where People Live

Figure 7: *DDS Population by Residential Setting, 2018*



[23] Department of Developmental Services Strategic Plan Summary, 2012-2014.

[24] The Community First Olmstead Plan. Massachusetts Executive Office of Health and Human Services, 2008. The latest plan is 2018: https://www.mass.gov/files/documents/2018/09/20/olmstead-final-plan-2018.pdf

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