

2016 PRELIMINARY MORTALITY REPORT



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



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Center for Developmental Disabilities
Evaluation and Research (CDDER)

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Dear Colleagues and Friends:

The Department of Developmental Services' Preliminary Annual Mortality Report for 2016 is enclosed. This is an independent review of data on deaths occurring in 2016 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 2016 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,

A handwritten signature in black ink that reads "Jane F. Ryder".

Jane Ryder

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MA DDS 2016 Preliminary Mortality Report

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, 2016.

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

Key points

- ❖ **POPULATION** – 26,296 adults were eligible for DDS services during 2016; of these adults, 431 died.
- ❖ **RATE** – Crude mortality rates have remained stable across years: 16.4 per thousand (2016); 18.0 per thousand (2015); and 16.6 per thousand (2014).
- ❖ **AGE** – Mortality rates were proportional with advancing age: for adults 75+ the mortality rate was 95.2 per thousand and for those aged 18-24 the rate was 2.8 per thousand. The average age at death of adults in the DDS population was 61.4 years
- ❖ **GENDER** – Male and female mortality rates were similar in 2016: 15.6 per thousand (male) and 17.4 per thousand (female).
- ❖ **RESIDENTIAL SETTING** – Mortality rates were lowest for adults living on their own or with family (6.7 per thousand) and those living in paid non-DDS settings (9.6 per thousand). Mortality rates were highest for people living in nursing homes (81.9 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 mortality reports for DDS 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 eligible¹ to receive services in the Meditech Consumer System from January 1 to December 31, 2016 and who died during the 2016 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 it supports and uses the findings to inform quality improvement efforts of the Department. As part of this effort, the University of Massachusetts 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 2016 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 on page 8.

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 law² 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 2016 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 2016, the Massachusetts DDS served 26,296 adults (18 years of age and older) with intellectual and developmental disabilities. A net increase of 2.2%, or 572 people, was seen in the mid-year adult consumer population from June 2015 to June 2016. 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). About 50% of the population live in their own home independently or with family, about 40% live in community-based supported residential settings, and the remainder live in other settings including nursing homes, 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 not typically available in 2016.

Mortality Statistics

In 2016, a total of **431 deaths** occurred for people eligible for DDS services, for a crude mortality rate of **16.4 deaths per thousand people**.⁴ The average age at death was 61.4 and the median⁵ age at death of adults in the DDS population was 62.0 in 2016. 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 2016. While the number of deaths dropped in 2016 after reaching a high in 2015, the population served also increased resulting in a mortality rate in 2016 that was the lowest in the last eight years. Changes in mortality rate were not significantly different between 2015 and 2016. Moreover, changes in the mortality rate between the previous five (5) years averaged (i.e., 2011-2015) and 2016 were not significantly different.⁶

Table 1: Mortality Trends in DDS Population, 2009 - 2016

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

Finally, the average age at death showed a non-significant⁷ decrease in 2016 to 61.4 years, which is consistent with previous years.

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 size between age groups and allows for age groups of different size to be compared to each other.

The relationship between age and rate of death for adults served by DDS

Table 2: Distribution Deaths by Age Group, 2016

Age Range	Number of Deaths	Percent of Deaths	Mortality Rate (per 1000)
18-24	15	3.5%	2.8
25-34	24	5.6%	3.9
35-44	22	5.1%	5.8
45-54	65	14.9%	14.5
55-64	126	29.3%	32.9
65-74	99	23.0%	49.0
75-84	50	11.6%	72.4
85 yrs & older	30	7.0%	201.3
TOTAL	431	100.0%	16.4

⁴ 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.

⁵ Median = the mid-point age if all deaths were ordered from youngest age to oldest age.

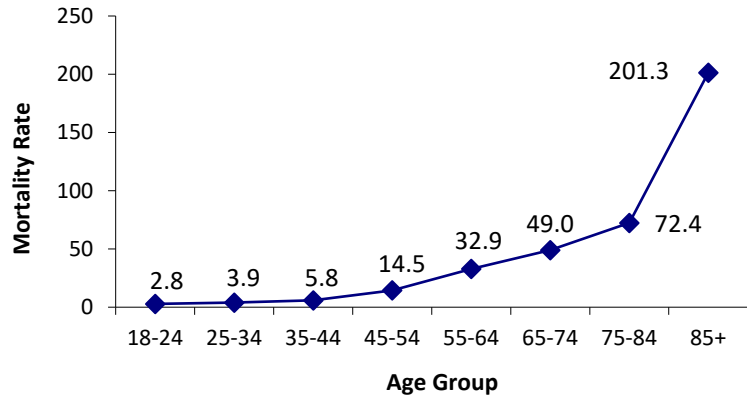
⁶ For 2015 to 2016, $\chi^2=1.92$, d.f.=1, p=0.165. For 2011-2015, $\chi^2=1.13$, d.f.=1, p=0.287.

⁷ t Stat=1.61, P(T<=t) two-tail=0.11, t Critical two-tail=1.96.

is displayed in Figure 1. The line in Figure 1 illustrates the increase of mortality rate with age. In the elderly 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 in 2016 by the total DDS population in 2016 and then multiplying by 1000.

Figure 1: Mortality Rate by Age Group, 2016



Gender

Gender proportions vary with age in the population served by DDS, 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 17.4 per thousand in 2016. For males, the adult mortality rate was 15.6 per thousand in 2016. Females served by DDS experience higher death rates than their male counterparts, a pattern which has been observed consistently in recent years. This may be in part because there is a higher proportion of females served in older age groups which have a higher death rate. There may also be differences in underlying risk between the two groups that could not be assessed during the scope of this analysis.

Table 3: Average Age at Death and Mortality Rate by Gender, 2016

Gender	DDS Population	No. Deaths	Percent of Deaths	Average Age at Death	Mortality Rate (n/1000)
Female	11,120	194	45%	62.3	17.4
Male	15,176	237	55%	60.6	15.6

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, 2016

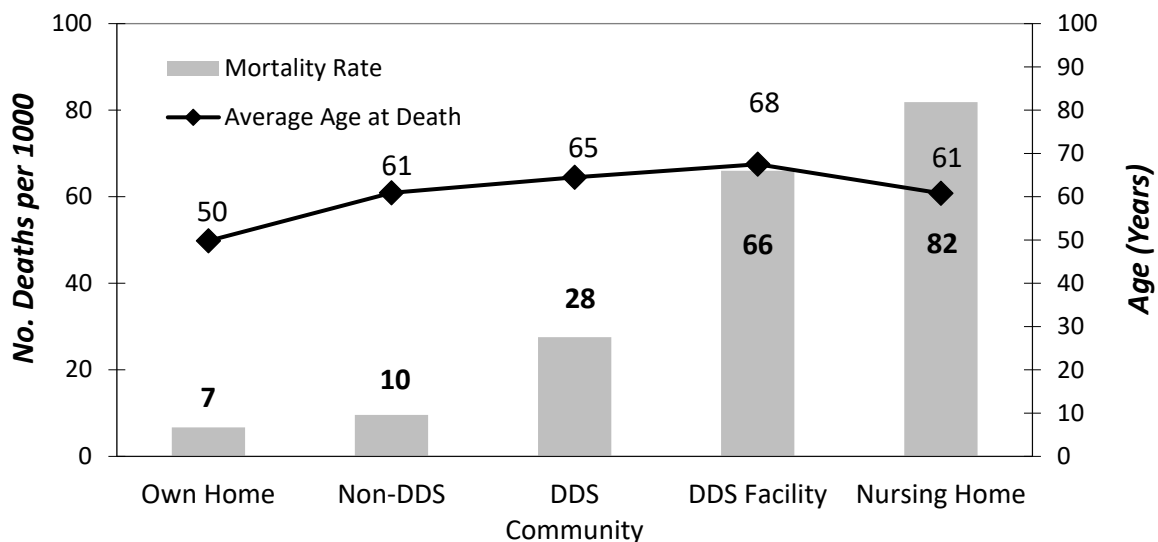
Residential Setting	DDS population	% of DDS population ⁸	% of DDS population ≥65 years	No. Deaths	Percent of Deaths	Average Age at Death	Mortality Rate (n/1000)
Own Home	12,814	48.7%	5%	87	20%	49.8	6.7
DDS Community	9,985	38.0%	17%	275	64%	64.5	27.5
Non-DDS	2,917	11.1%	9%	28	7%	60.9	9.6
DDS Facility	409	1.6%	39%	27	6%	67.5	66.0
Nursing Home	171	0.7%	27%	14	3%	60.8	81.9
TOTAL	26,296	100.0%	11%	431	100%		16.4
Average						61.4	

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. Historically, 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.

The average age of death decreased across all care settings compared to 2015. As shown in Table 4 and Figure 2, the average age at death was lowest for people living in their own home (49.8 years). The average age at death was highest for those living in DDS Facilities (67.5 years) and DDS Community settings (64.5 years). This is an expected pattern because the average age of adults served by DDS who

Figure 2: Mortality Rate and Average Age at Death by Type of Residence, 2016



⁸ Total may sum to greater than 100% due to duplication in enrollment data.

reside in their own home is often 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 just under half of the individuals served by DDS in 2016, as in 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 2016. The crude adult rate of death for those living in their own home was 6.7 per thousand in 2016, which was slightly lower than last year but consistent with previous years.⁹ 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 (5%); this is reflected in the relatively low average age at death of 49.8 years. The crude adult mortality rates for people living in their own home continues to be lower than the crude mortality rate of 8.2 per thousand for all ages of the general population of Massachusetts.¹⁰

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. The crude adult mortality rate for people served by DDS living in the DDS Community was 27.5 per thousand in 2016, which is not significantly different from 2015 data.¹¹ The average age at death (64.5) 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 in total 13% of the entire DDS population. It is important to note that such small 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

⁹ Z-test of the proportions of deaths to population for the subgroup of those living independently (Own Home) in 2016 compared to 2015 yielded $z = -0.69$; there was no significance difference between 2016 and 2015.

¹⁰ *Massachusetts Deaths 2014*. Office of Data Management and Outcomes Assessment, Massachusetts Department of Public Health, October 2016. Table 1: Trends in Mortality Characteristics, Massachusetts: 2004 – 2014. <http://www.mass.gov/eohhs/docs/dph/research-epi/death-data/death-report-2014.pdf>.

¹¹ Z-test of the proportions of deaths to population for the subgroup of those living in the DDS Community in 2016 compared to 2015 yielded $z = -1.4$.

settings. Because of this, demographics among this group tend to vary greatly, which contributes to annual fluctuations in mortality patterns within this setting. Twenty-eight people in 2016 served by DDS living in Non-DDS residences died. The adult mortality rate for this setting was 9.6 per thousand in 2016, which was not significantly¹² higher than the 2015 rate for this setting. This setting also had the second lowest mortality rate of all DDS residential settings in 2016.

DDS Facilities

The population in this setting is shrinking as efforts are made to shift facility-based residential supports to community-based supports. Between 2015 and 2016, the total population decreased by over 6.1% from 436 individuals to 409 individuals. The population remaining in facilities is the oldest of all residential settings, with more than 39% over the age of 65. In 2016, 27 people died for a crude adult mortality rate of 66.0 per thousand. The mortality rates in 2016 and 2015 for this setting were not significantly different.¹³ 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.¹⁴ As a result, people living in this setting have some of the highest care needs of all people served by DDS and over one quarter 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 2016, 14 people who were residing in nursing homes (for more than 30 days) died. This setting had a crude adult mortality rate of 81.9 per thousand in 2016, representing the highest rate of death of all residential settings. No significant difference was observed between 2015 and 2016.¹⁵ The mortality rate for this setting is likely affected by increased efforts to divert people from living in nursing homes when possible, resulting 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.

¹² Z-test of the proportions of deaths to population for the subgroup of those living in Non-DDS settings in 2016 compared to 2015 yielded $z = 1.7$.

¹³ Z-test of the proportions of deaths to population for the subgroup of those living in DDS Facilities in 2016 compared to 2015 yielded $z = -0.7$.

¹⁴ <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Preadmission-Screening-and-Resident-Review-PASRR.html>.

¹⁵ Z-test of the proportions of deaths to population for the subgroup of those living in Nursing Homes in 2016 compared to 2015 yielded $z = -0.1$.

Hospice

In 2016, the number and proportion of deceased individuals who received hospice support increased to 207 or 48.1% compared to 2015. The rate of hospice use is very similar to the most recently available data for the general population where 44.6% of deaths in the US were reported to use hospice services in 2011,¹⁶ which is in line with expectations given the frequency of end stage conditions observed in causes of death.

Table 5: Number of Individuals Receiving Hospice Support, 2015-2016

Hospice	2015		2016	
	No. Deaths	Percent of Deaths	No. Deaths	Percent of Deaths
Yes	204	44.1%	207	48.1%
No	239	51.6%	204	47.4%
Unknown	20	4.3%	20	4.4%
TOTAL	463	100.0%	431	100.0%

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 is 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. 294 mortality reviews were required according to these criteria for deaths occurring in 2016. Of the 294 required reviews, 283 were completed, for a completion rate of 96%. Three (3) requested mortality reviews of 2016 deaths were also completed in addition to those required.

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

¹⁶ As reported in the National Hospice and Palliative Care Organization Facts and Figures: Hospice Care in America report 2012 Edition which cite the 2011 NHPCO National Data Set and/or NHPCO Member Database and the 1st Quarter 2012, Centers for Medicare and Medicaid Services (CMS) Provider of Service File (POS). http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf.

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.¹⁷

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

¹⁷ "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."

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 2009–2016. The same number of deaths were investigated in 2016 as in 2015 and this count was consistent with numbers prior to 2014. DDS conducted 16 investigations and DPPC conducted 1 investigation in 2016. Law enforcement reviewed 1 case in 2016.

Table 6: Summary of Investigations, 2009 to 2016

Type of Activity	2009	2010	2011	2012	2013	2014	2015	2016
DDS Investigation	13	5	3	10	9	6	10	16
DPPC Investigation	3	3	1	3	3	2	2	1
Refer to Other Agency	3	4	4	2	6	0	2	2
District Attorney/ Law Enforcement Investigation	3	10	12	13	9	5	4	1
Other/dismissed ¹⁸	2	3	2	4	2	2	5	3
Resolved Fairly & Efficiently	1	1	0	1	0	0	0	0
Total Deaths Investigated	25	26	24	20	21	10	23	23

Table 7 presents the findings of investigations by either DDS or DPPC. Investigations regarding six (6) of the deaths that occurred in 2016 found the allegations were substantiated, meaning the death was the result of abuse, neglect, or omission. Twelve investigations in 2016 were found to be unsubstantiated allegations. The remaining cases were either dismissed, referred for administrative review, or referred to other agencies.

Table 7: Findings in Cases Investigated by DDS or DPPC, 2009 to 2016
(NOTE: Includes cases deferred to law enforcement)

Findings	2009	2010	2011	2012	2013	2014	2015	2016
Number of Substantiations	3	5	4	5	3	2	6	6
Pending	1	1	2	0	1	0	0	0

¹⁸ 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 2016 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 the discovery of a person's death according to DDS policy. This report includes statistics on all deaths of people who died in calendar year 2016 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, 2016.¹⁹ 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:

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

¹⁹ 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

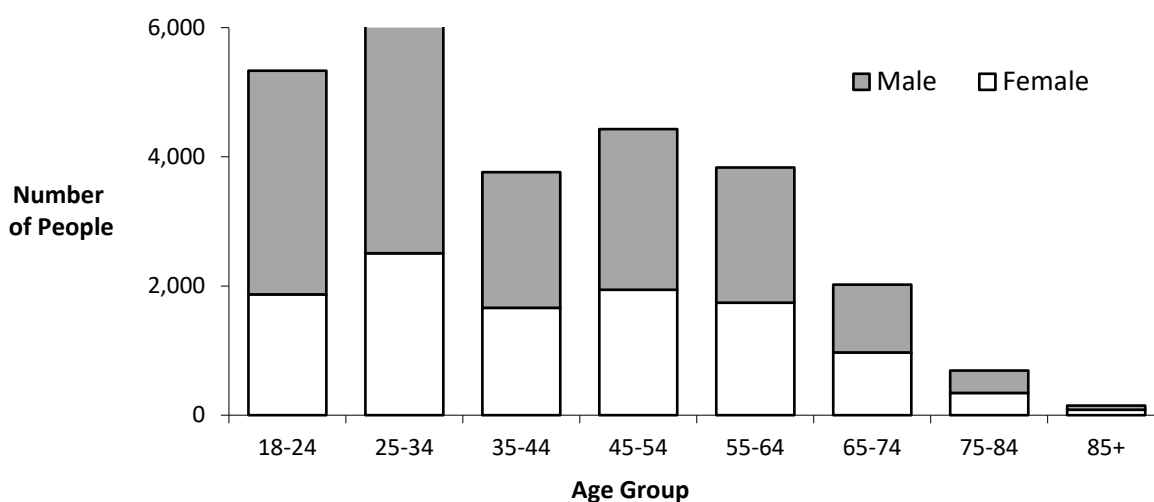
Age Characteristics

Table 8 and Figure 3 presents the age distribution for the DDS population in 2016. With the exception of population groups under 25 and over 84, populations are in 10-year age groups. The largest populations are in age bands between 18 and 34, and 45-54, with over 4,400 per age band. Most age bands experienced less than 5% fluctuation between 2015 and 2016, except for the age group 25-34 years which experienced a slightly larger 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 (89% compared to 85%).²⁰ Also, while only 0.6% of the MA DDS population is age 85 or older, almost 2% of the Massachusetts general adult population is within this age group.

Table 8: Population Served by DDS by Age Group and Gender, 2016

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1,870	2,507	1,662	1,942	1,741	970	345	83	11,120
Male	3,463	3,570	2,100	2,488	2,093	1,050	346	66	15,175
Total	5,333	6,077	3,762	4,430	3,834	2,020	691	149	26,296

Figure 3: Population Served by DDS, by Age Group and Gender, 2016



²⁰ Annual Estimates of the Resident Population for Selected Age Groups by Sex for the United States, States, Counties, and Puerto Rico Commonwealth and Municipios: April 1, 2010 to July 1, 2014. U.S. Census Bureau, Population Division. June 2015.

Figure 4 presents the change in the DDS population between calendar years 2015 and 2016. Between 2015 and 2016, there were more people served in most age groups, but the largest gains were in the 25-34 age group. As shown in Figure 5, patterns differed slightly by gender with larger proportional increases in the male population ages 25-34 and 55-64.

Figure 4: Population Served by DDS, Change in Number and by Percent, 2015-2016

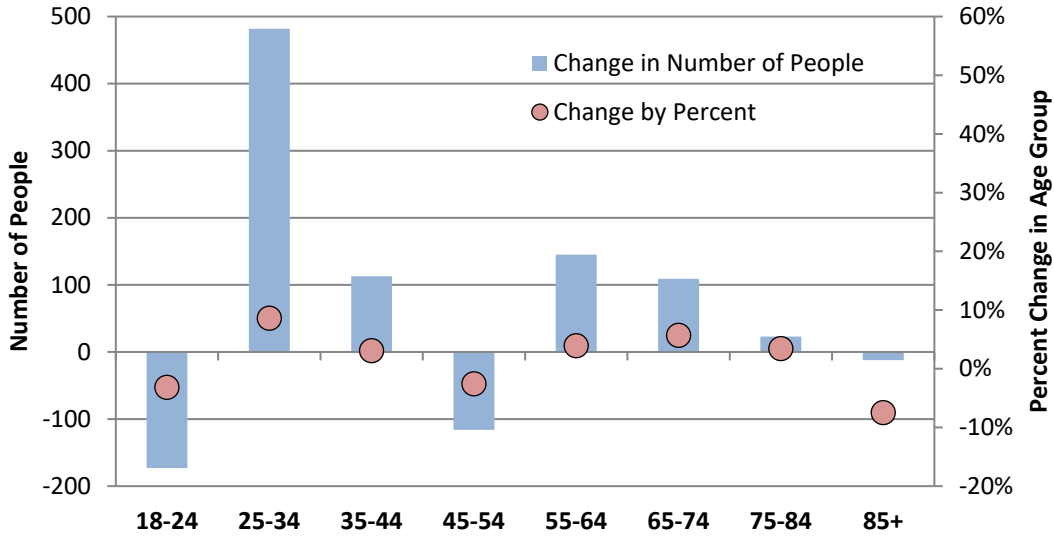


Table 9: Population Served by DDS, Change²¹ by Age Group, 2015 to 2016

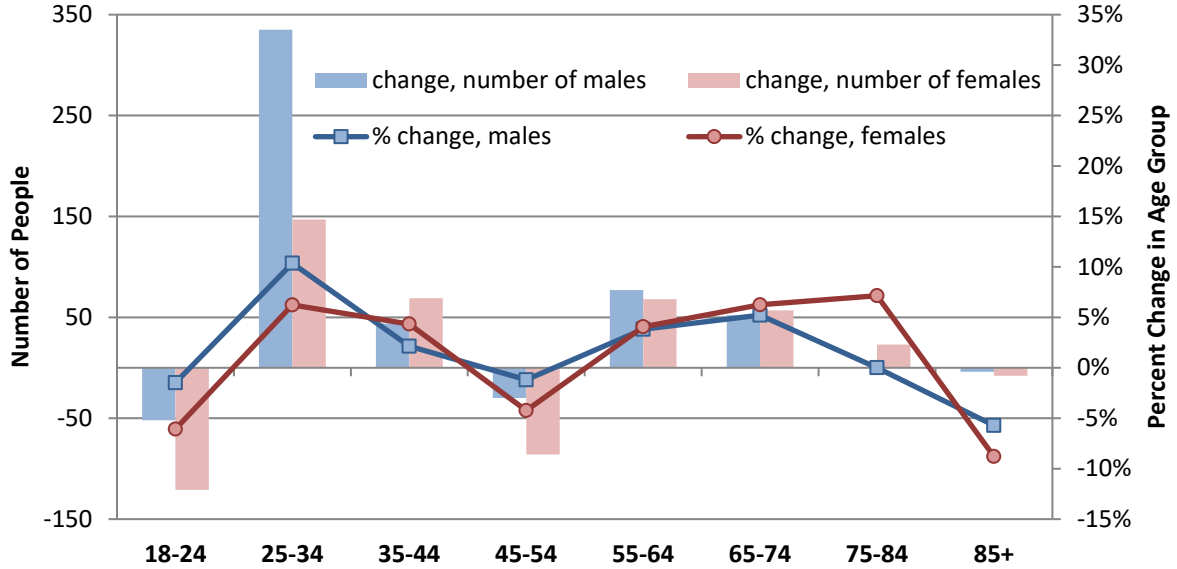
Age Group	Net Change in Population	% Change in Pop	Resulting % Change in DDS Consumer Population from 2015
18-24	-173	-3.1%	-0.7%
25-34	482	8.6%	1.9%
35-44	113	3.1%	0.4%
45-54	-116	-2.6%	-0.5%
55-64	145	3.9%	0.6%
65-74	109	5.7%	0.4%
75-84	23	3.4%	0.1%
85+	-12	-7.5%	<0.1%
Total	572	2.2%	2.2%

As shown in Table 8 and Figure 5, most young adults coming into adult services are males. Although just under twice as many males as females entered the 18-24 year age group in 2016 there was a decrease in the total size of the population in the 18-24 cohort and in the gender percentages compared to 2015 with the relative percent decrease in young males (-1.5%) lower than for females (-6.1%). It is not known what effect this pattern may have on mortality patterns in the current year or future years. In older age groups, men and women are showing similar changes in population size, with the exception of the 75-84

²¹ Gross population change reflects the migration of living people between age groups. The figures 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.

age band where women alone showed an increase; however, population sizes in these older age groups remain very small.

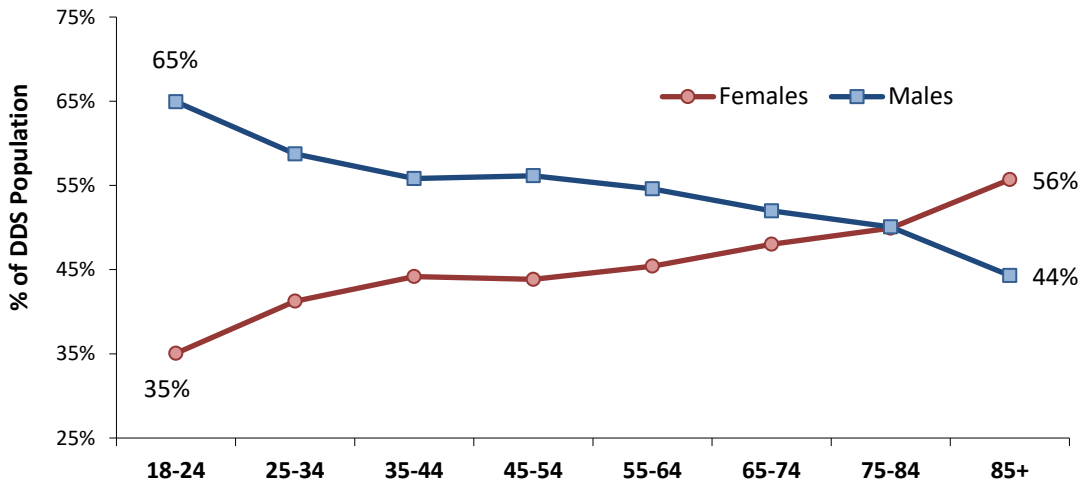
Figure 5: Population Served by DDS, Change by Gender, 2015-2016



Gender Characteristics

The gender distribution in the 2016 adult DDS population is similar to previous years. The proportion of men served by DDS is highest for individuals aged 18-24 and decreases by age group, as illustrated in Figure 6. The proportion of men among people served is higher for all adult age groups except for older adults ages 65-84 where the proportions are equal between genders. For those ages 85 and above, there is a higher proportion of women. The shift in gender distributions in the elderly population is similar to what other states report seeing in the general population. Since 2010, the gender distribution in the oldest age group has been consistently more similar between genders.

Figure 6: Gender Distribution by Age, 2016



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: 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.

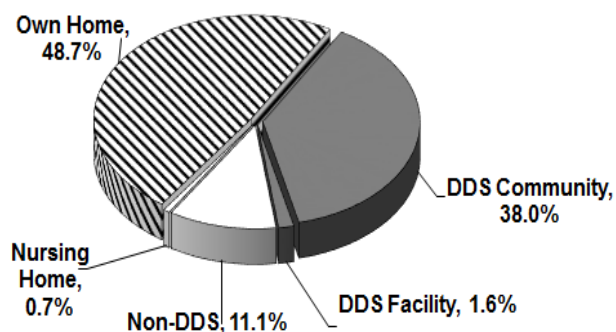
In 2015, 48.6% of the adults served by DDS resided in their own home, which includes people living independently or with their family. By 2016, this increased slightly to 48.7%.

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 2016, about 38.0% of adults served by DDS lived in a community residential program, and 1.6% lived in DDS facilities.

The number of people living in DDS facilities continues to decline annually 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 facilities²², 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."²³

In 2015, about 11.6% of adults served by DDS resided either in programs that are funded privately or by other agencies or in nursing homes. In 2016, this portion increased slightly to 11.8% of the DDS population who resided in Non-DDS or nursing home settings, as seen in Figure 7. The portion of the population living in the "Non-DDS" setting has increased from 5.3% of the population in 2009, largely due to growth in the use of Adult Foster Care services.

Figure 7: Population Served by DDS by Residential Setting, 2016



²² Department of Developmental Services Strategic Plan Summary, 2012-2014.

²³ 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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