Eunice Kennedy Shriver Center
UMASS MEDICAL SCHOOL
CDDER
Center for Developmental Disabilities Evaluation and Research

2015 Preliminary Mortality Report

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

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Dear Colleagues and Friends:

Enclosed is the Department of Developmental Services Preliminary Annual Mortality Report for calendar year 2015. The report is compiled by the Center for Developmental Disabilities Evaluation and Research (CDDER) of the University of Massachusetts Medical School. The report analyzes information on all deaths occurring in calendar year 2015 for all persons 18 years of age or older who have been determined to be eligible for DDS supports. This is the ninth year in which DDS has commissioned an independent review of all deaths.

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.

With the assistance of CDDER, DDS has made significant progress in improving our standardized reporting systems, strengthening our clinical mortality review process and improving the comparability of our data to state and national death statistics.

This report is reviewed by the Statewide Mortality Review Committee as well as our Statewide Quality Council to assist DDS in its ongoing commitment to supporting the health and quality of life of the individuals we support. I remain committed to the importance of this independent mortality report as a vital and critical component of the Department's quality management and improvement system and an important step in our shared organizational learning process.

Sincerely yours,

Jane F. Ryder
Commissioner

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Executive Summary

This report presents population and mortality information about adult (18 years of age and older) service recipients of the Massachusetts Department of Developmental Services (DDS) for the one-year period between January 1, 2015 and December 31, 2015.

Annual mortality reports are part of the Massachusetts DDS' robust quality management and improvement system. DDS' established process for death reporting and mortality review provide the data included in this report, written by the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER). Mortality findings are used to inform quality improvement efforts for supports provided by DDS.

In the middle of calendar year 2015, DDS served 25,724 adults with intellectual and developmental disabilities. In November 2014, eligibility for DDS services was expanded by law to include people with certain developmental disabilities who experience multiple, substantial functional limitations. In 2015, the population served in the youngest age groups increased by 3.9%, continuing a pattern observed since 2012. Changes between age groups of service recipients may be affected by people aging into adult services, aging into adjoining age bands, people relocating out of the state, and people that have died.

In 2015, a total of **463 deaths** occurred for people eligible for DDS services, for a crude mortality rate of **18.0 deaths per thousand people**. The average age at death of adults in the DDS population was 63.1 years in 2015. Statewide mortality statistics in 2015 do not show a significant change in the rate of death for the population from 2014.

This report is preliminary because it does not yet contain analyses of causes of death, which require death certificate data from the Massachusetts Department of Public Health. Once the 2015 vital statistics dataset is finalized for release and data are analyzed, a final report will be issued including information on causes of death.

Patterns of mortality in the DDS population are influenced by a number of factors:

- **Age**: Mortality rates show a proportional relationship with advancing age – the youngest age groups have the lowest rates of death and the mortality rate increases with age. The average age of death was similar to prior years.
- **Gender**: There was not a statistically significant difference observed in mortality between genders in 2015. This pattern is in contrast to prior years (2012-2014) where females had a statistically higher rate of death than males.
- **Residential Setting:** Consistent with expectations, substantial differences in mortality exist between residential settings. Mortality rates were lowest for people living in paid services outside of DDS (5.7 per thousand) and people living at home or with family (7.5 per thousand). People living in these settings tend to be younger and frequently have fewer support needs than people in other residential settings. Mortality rates were highest for people living in nursing homes (85.1 per thousand) due to advanced age and/or serious health conditions. The DDS Facilities mortality rate was 78.0 per thousand and the average age of death was the most advanced of all settings at 69.9 years, reflecting a gradual increase over time as people are moved to other settings in the process of closing these institutional settings. The rate of death in the 'DDS Community' was similar to previous years (31.0 per thousand). Overall, the relationship between type of residence and mortality are consistent with prior years and with trends present in other state intellectual and developmental disability systems.

2015 Preliminary Mortality Report

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) during the periods of January 1 and December 31, 2015 (calendar year 2015). The mortality information in this report includes all adults who were eligible[a] to receive services in the Meditech Consumer System during these periods and who died during the calendar year. MassHealth members on the Moving Forward Plan (MFP) Medicaid waivers and the Acquired Brain Injury Medicaid waivers operated by DDS or by the Massachusetts Rehabilitation Commission are not included in this report.

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 the year 2000. In order to prepare each annual report, CDDER compiles mortality information from DDS records as well as other external sources and performs mortality and population analyses contained 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:

- **Are at least 18 years of age;**
- **Receive a minimum of 15 hours of residential support that is 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 of 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 2015 that includes patterns of mortality across demographic factors (age, gender, and residential settings), but does not include patterns related to causes of death and associated benchmarks. In its analysis of causes of death, CDDER uses information from death certificates collected by the Massachusetts Department of Public Health. As of the writing of this report, the death certificate data for 2015 had not yet been finalized for analysis. A final report will be issued once the death certificate information is fully available from the state public health department.

[a] See description of expanded eligibility for DDS services starting in November 2014 on page 6.

OVERVIEW OF POPULATION 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[1] 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 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 2015 are eligible for a narrower range of services than adults who are eligible due to an intellectual disability.[b] 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 2015, the Massachusetts DDS served 25,724 adults (18 years of age and older) with intellectual and developmental disabilities. A net increase of about 3.9%, or 974 people, was seen in the mid-year adult consumer population from June 2014 to June 2015. See Appendix B for more details 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 lives in their own home independently or with family, about 40% living 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.

MORTALITY DURING 2015

This section contains information on the deaths of people with intellectual and developmental disabilities who were 18 years of age or older at the time of death and who were eligible for DDS services during calendar year 2015.[c] Appendix A describes the methodology used to collect and analyze the information and data contained in this section.

[b] Community Developmental Disability Services available under expanded eligibility include services: 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, such as 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 available in 2015.

[c] Includes expanded eligibility for DDS services starting in November 2014 (see description above).

Mortality Statistics

In 2015, a total of **463 deaths** occurred for people eligible for DDS services, for a crude mortality rate of **18.0 deaths per thousand people**.[2] Both the average and median[d] age at death of adults in the DDS population was 63.1 years in 2015.

Table 1
Mortality Trends in DDS, 2009 - 2015

Year	No. Deaths	Mortality Rate (No. Deaths/1000)	Ave. 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

Table 1 shows the number of deaths, mortality rates and average age at death for the DDS population for 2009 through 2015. While the number of deaths was higher in 2015 than in recent years, the population served also increased resulting in a mortality rate in 2015 that was similar to previous years. Changes in mortality rate were not significantly different between 2014 and 2015.[e] The average age at death showed a non-significant[f] increase in 2015 to 63.1 years, which is the highest average age at death since the first DDS mortality report in 2000.

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.

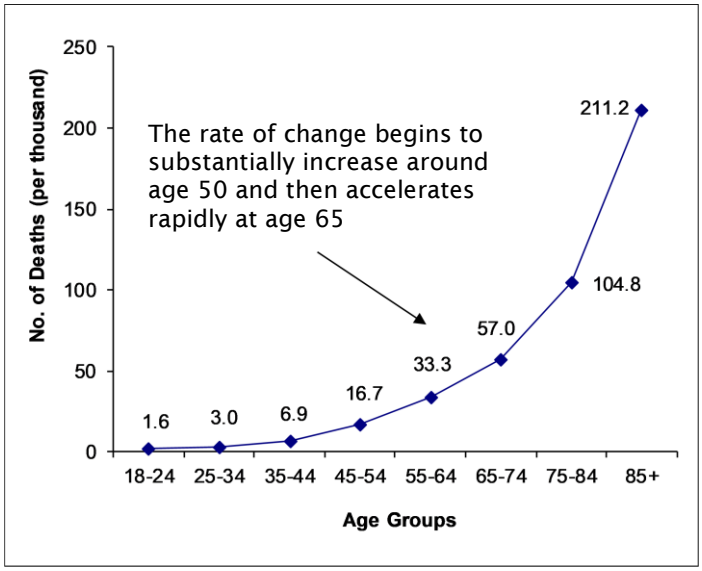
Table 2
Distribution of Deaths by Age Group, 2015

Age Range	2015		
	No. Deaths	Percent of Deaths	Crude Death Rate (No. per 1000)
18-24 yrs	9	1.9%	1.6
25-34 yrs	17	3.7%	3.0
35-44 yrs	25	5.4%	6.9
45-54 yrs	76	16.4%	16.7
55-64 yrs	123	26.6%	33.3
65-74 yrs	109	23.5%	57.0
75-84 yrs	70	15.1%	104.8
85 yrs & older	34	7.3%	211.2
Total	**463**	**100.0%**	**18.0**

[d] Median = the middle age if all deaths were ranked by age
[e] For 2014 to 2015, χ^2=1.31, d.f.=1
[f] χ^2=0.003, d.f.=1 for 2014-2015 and χ^2=0.37, d.f.=1 for 2009-2015

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 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.

Figure 1
Mortality Rate by Age Group
Adults Served in 2015



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 19.1 per thousand in 2015. For males, the adult mortality rate was 17.2 per thousand in 2015. 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
No. Deaths, Average Age at Death and Death Rate by Gender, 2015

Gender	Adult Population	No. Deaths	Percent of Deaths	Average Age at Death	Death Rate (n/1000)
Female	10,971	209	45%	63.2	19.1
Male	14,753	254	55%	62.9	17.2

RESIDENCE

Adults eligible for DDS services live in one of five general types of residential settings: their own home 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. Mortality statistics for these residential categories are displayed in Table 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.

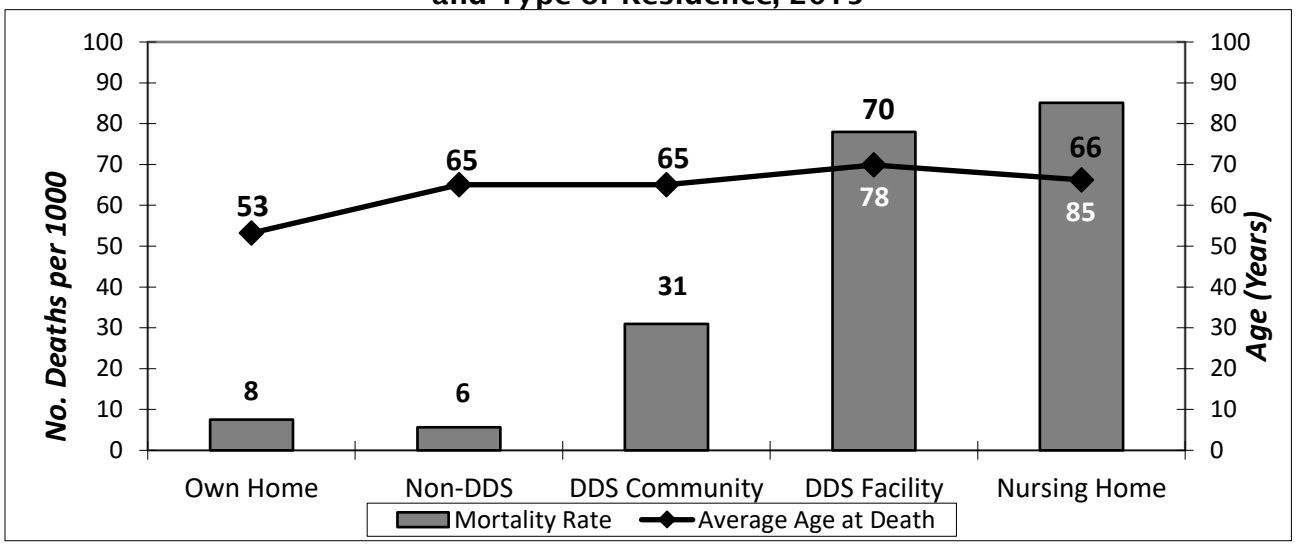
The average age of death increased a small amount across all care settings compared to 2014. As shown in Table 4 and Figure 2, the average age at death was lowest for people living in their own home (53.2 years). The average age at death was highest for those living in DDS Facilities (69.9 years) and Nursing Home settings (66.2 years). This is an expected pattern because the average age of adults served by DDS who 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.

Table 4
Age and Mortality by Type of Residential Setting, Adults Served by DDS, 2015

Residential Setting	Adult Population (No. People)	% of DDS population[9]	% of Population 65+ yrs	No. Deaths	Percent of Deaths	Average Age at Death (in years)	Mortality Rate (n/1000)
Own Home	12,498	48.6%	5%	94	20%	53.2	7.5
DDS Community	9,785	38.0%	17%	303	65%	65.1	31.0
Non-DDS	2,817	11.0%	9%	16	3%	65.1	5.7
DDS Facility	436	1.7%	36%	34	7%	69.9	78.0
Nursing Home	188	0.7%	28%	16	3%	66.2	85.1
Total (Statewide)	25,724	100.0%	11%	463	100%		17.9
Average						63.1	

[9] Total may sum to greater than 100% due to duplication in enrollment data.

Figure 2
Relationship between Mortality Rate, Average Age at Death, and Type of Residence, 2015



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 2015, similar to previous years. The majority of services provided to people eligible for DDS services under the expanded eligibility starting in Nov 2014 would be proved to people in this setting.

This subgroup had the second lowest mortality rates in 2015. The crude adult rate of death for those living in their own home was 7.5 per thousand in 2015, which was slightly higher than previous years. 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 53.2 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.[3]

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 31.0 per thousand in 2015, which is not significantly different from 2014 data.[h] The average age at death (65.1) 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.

[h] Z-test between proportions of residential-specific deaths and populations, z = 1.8

Other Residential Settings

The remaining three residential settings, Non-DDS funded supported settings, DDS facilities and nursing homes, represent in total about 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 settings. Because of this, demographics among this group tend to vary greatly, which contributes to annual fluctuations in mortality patterns within this setting. Sixteen people in 2015 served by DDS living in Non-DDS residences died. The adult mortality rate for this setting was 5.7 per thousand in 2015, which was significantly[i] lower than the 2014 rate for this setting. This setting also had the lowest mortality rate of all DDS residential settings in 2015.

DDS Facilities. The population in this setting is shrinking as efforts are made to shift facility-based residential supports to community-based supports. Between 2014 and 2015, the total population decreased by over 13% from 500 individuals to 436 individuals. The population remaining in facilities is the oldest of all residential settings, with more than 36% over the age of 65. In 2015, 34 people died for a crude adult mortality rate of 78.0 per thousand. The mortality rates in 2015 and 2014 for this setting were not significantly different.[j] 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.[4] 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 2015, 16 people who were residing in nursing homes (for more than 30 days) died. This setting had a crude adult mortality rate of 85.1 per thousand in 2015, representing the highest rate of death of all residential settings. No significant difference was observed between 2014 and 2015.[k] 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.

[i] Z-test between proportions of residential-specific deaths and populations, z = -2.6

[j] Z-test between proportions of residential-specific deaths and populations, z = 1.5

[k] Z-test between proportions of residential-specific deaths and populations, z = -1.0

Hospice Use

In 2015, the proportion of deceased individuals who received hospice support increased to 204 or 44.1% compared to 2014. 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,[5] 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

	2014		2015	
Hospice	No. Deaths	Percent of Deaths	No. Deaths	Percent of Deaths
Yes	181	43.9%	204	44.1%
No	214	51.9%	239	51.6%
Unknown	17	4.1%	20	4.3%
Total	**412**	**100.0%**	**463**	**100.0%**

MORTALITY REVIEW PROCESS AND COMMITTEE

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-hrs 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 submitted to the Regional and/or Central Review Committee for analysis, confirmation of cause of death and follow-up if indicated. A total of 317 reviews were required according to these criteria for deaths occurring in 2015. A total of 310 of the required reviews were completed, for a completion rate of 98%. DDS Central Office is conducting follow-up activities to correct process issues related to missed reviews and ensure they are completed. Twelve requested mortality reviews of 2015 deaths were also completed in addition to those required.

Mortality Review Procedure

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 to Central Office upon completion and review by the Regional Director, Facility Director or their designee within 30 days of the death.

A review of each case is conducted by the Regional Mortality Review Committee which consists of at least 1 Registered Nurse, 1 Risk Manager and 1 representative from the Central Mortality Review Committee. Other members may be 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, at least one representative from each of the Regional Mortality Review Committees, two physicians (one DDS and one a community practitioner), 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, information is clarified and 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 in order to determine if 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 forwards all reports to the Disabled Persons Protection Commission (DPPC). 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) conducts an investigation into 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.[l]

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 2007 – 2015. There were more deaths investigated in 2015 than in 2014 but this count was consistent with numbers prior to 2014. DDS conducted 10 investigations and DPPC conducted 2 investigations in 2015. Law enforcement reviewed 4 cases in 2015.

[l] "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."

Table 6
Summary of Investigations, 2007 to 2015

Type of Activity	2007	2008	2009	2010	2011	2012	2013	2014	2015
DDS Investigation	9	8	13	5	3	10	9	6	10
DPPC Investigation	10	5	3	3	1	3	3	2	2
Refer to Other Agency	7	0	3	4	4	2	6	0	2
District Attorney/Law Enforcement Investigation	9	10	3	10	12	13	9	5	4
Other/dismissed[m]	5	4	2	3	2	4	2	2	5
Resolved Fairly and Efficiently	1	0	1	1	0	1	0	0	0
Total Number of Deaths Investigated	34	18	25	26	24	20	21	10	23

Table 7 presents the findings of investigations by either DDS or DPPC. Investigations regarding 6 of the deaths that occurred in 2015 found the allegations were substantiated, meaning the death was the result of abuse, neglect or omission. Ten investigations in 2015 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, 2007 to 2015
(Includes cases deferred to law enforcement)

Findings	2007	2008	2009	2010	2011	2012	2013	2014	2015
Number of Substantiations	3	1	3	5	4	5	3	2	6
Pending	3	2	1	1	2	0	1	0	0

[m] Complaint was Dismissed, Resolved w/o 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 2015 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 an person's death according to DDS policy. This report includes statistics on all deaths of people who died in calendar year 2015 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, 2015.[n] The Meditech system contains information on every person eligible for DDS supports, including those who may not be receiving DDS services currently. In addition, DDS made Mortality Review forms and clinical notes available to CDDER for verification of information about the decedents subject to Clinical Mortality Review.

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
- Ricci class membership status
- Rolland class membership status
- Boulet class membership status

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:

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

[n] 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 2015. 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 4,500 per age band. Most age bands experienced less than 5% fluctuation between 2014 and 2015, except for the age groups under 35 years which experienced slightly larger increases (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%)[6]. 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
2015 DDS Population

Age	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Female	1,991	2,360	1,593	2,028	1,673	913	322	91	10,971
Male	3,515	3,235	2,056	2,517	2,016	998	346	70	14,753
Total	5,506	5,595	3,649	4,545	3,689	1,911	668	161	25,724

Figure 3
Distribution of the Population Served by DDS by Age and Gender, 2015

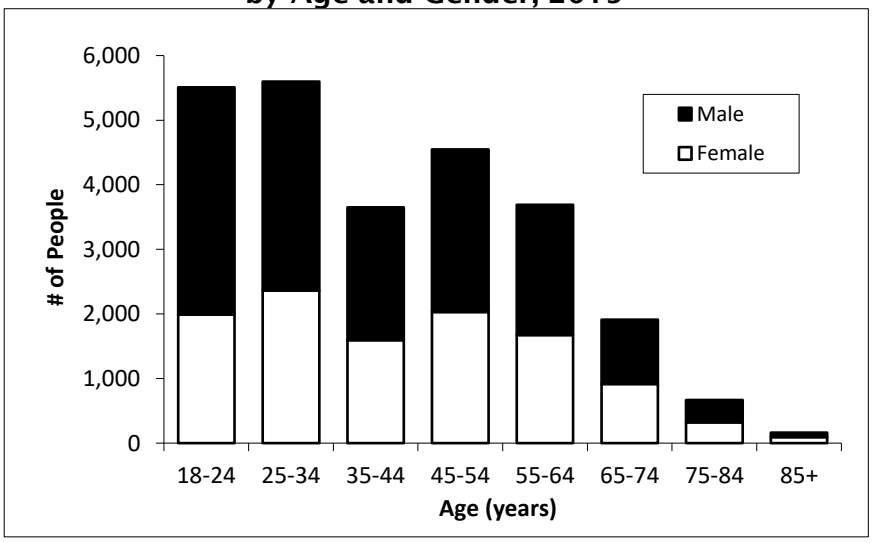


Figure 4 presents the change in the DDS population between calendar years 2014 and 2015. Between 2014 and 2015, there were more people served in almost all age groups, but the largest gains were in the older age groups. As shown in Figure 5, patterns differed slightly by gender with larger proportional increases in the male population 18-24 and at 55-64.

Figure 4
DDS Population Change, 2014-2015

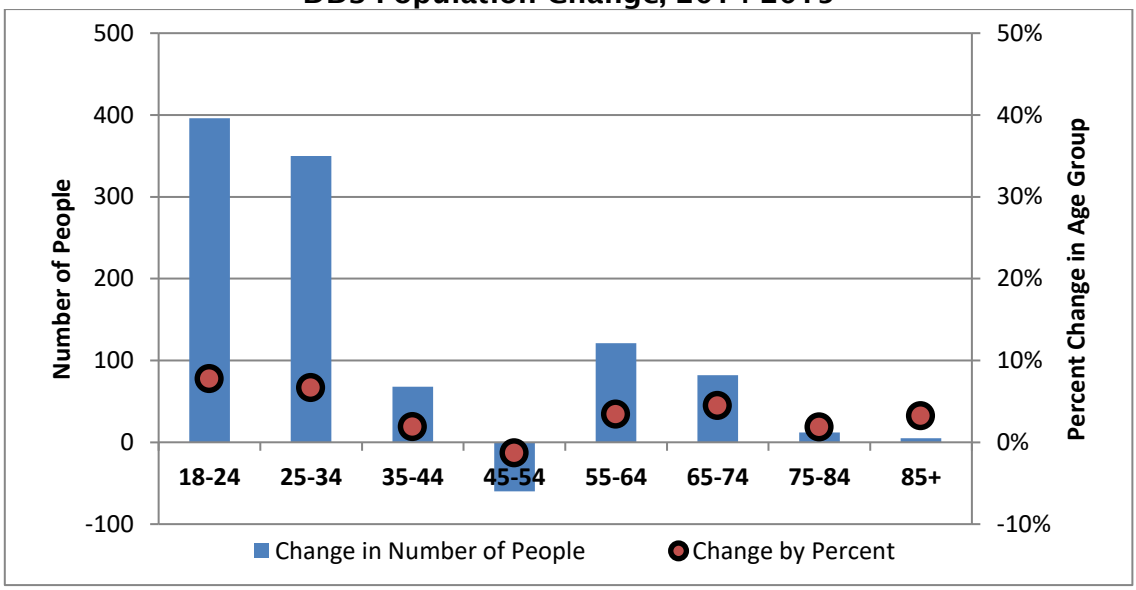


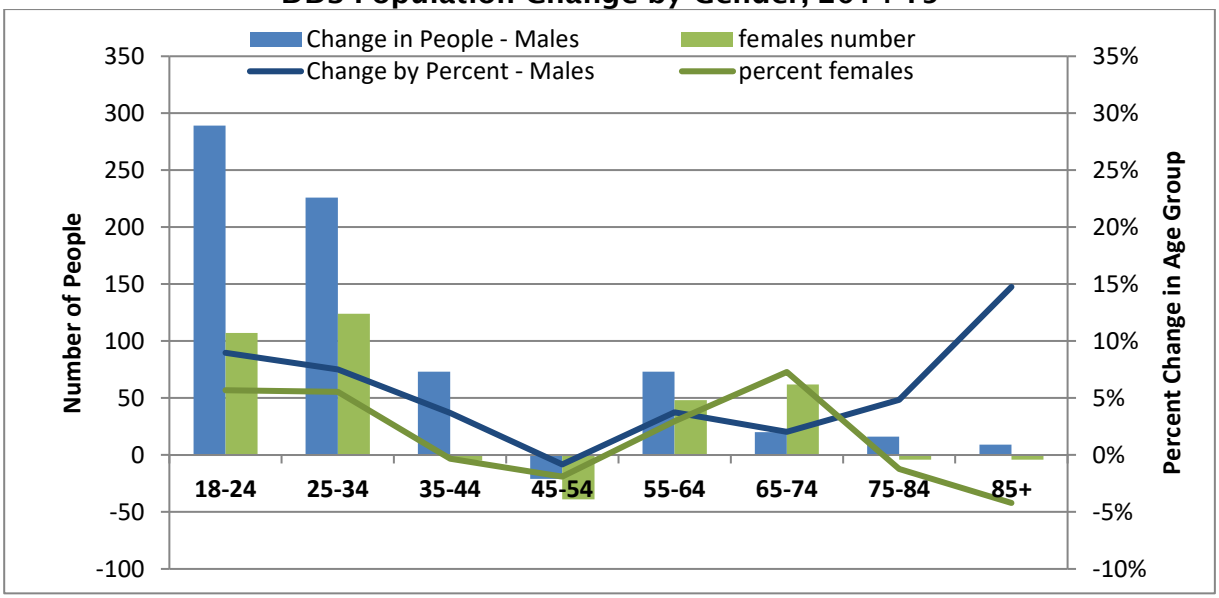
Table 9
Annual DDS Population Change within Age Group
A Comparison of 2014 and 2015

Age Group	Gross Population Fluctuation[o]		
	People	% Change within Age Group	Resulting % Change in DDS Consumer Population from 2014
18-24	396	7.7%	1.6%
25-34	350	6.7%	1.4%
35-44	68	1.9%	0.3%
45-54	-60	-1.3%	-0.2%
55-64	121	3.4%	0.5%
65-74	82	4.5%	0.3%
75-84	12	1.8%	<.1%
85+	5	3.2%	<.1%
Total	974	3.9%	3.9%

As shown in Figure 5, the majority of young adults coming into adult services are males. Over twice as many males as females entered the 18-24 year age group in 2015, and the relative percent increase in young males was also higher than for females. 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 are showing larger relative increases in population size than females which are showing relative decreases in population; however population sizes in these older age groups remain very small.

[o] 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 death over the course of the year. The percent increase in the population will not match the net population increase.

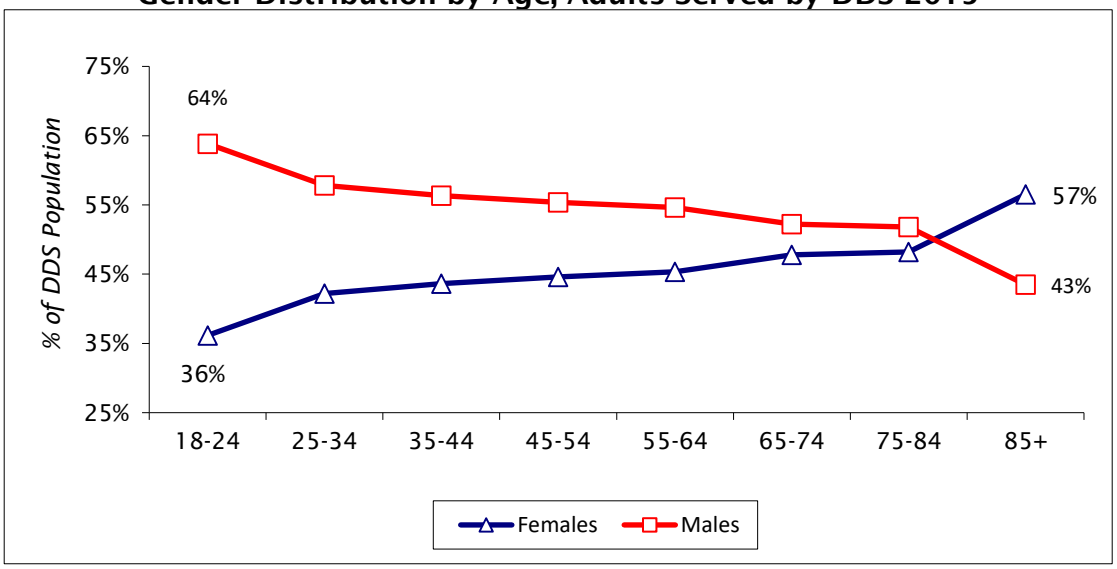
Figure 5
DDS Population Change by Gender, 2014-15



Gender Characteristics

The gender distribution in the 2015 adult DDS population is similar to previous years. The proportion of men served by DDS is highest for individuals age 18-24 and decreases by age group, as illustrated in Figure 6. The proportion of men is higher for all adult age groups except for older adults ages 65-84. 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 reports from other states and that seen in the general population. Since 2010, the gender distribution in the oldest age group has consistently been more similar between genders.

Figure 6
Gender Distribution by Age, Adults Served by DDS 2015



Residential Setting Characteristics

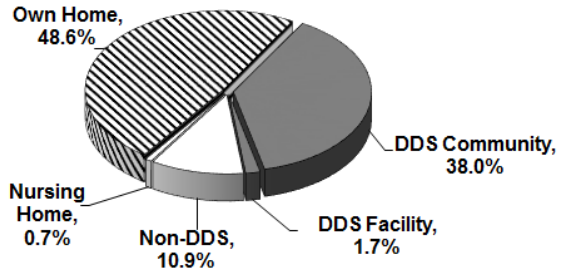
Adults receiving services from DDS reside in a variety of different settings. In this report, the residential settings are grouped into five categories: their own home, either independently or with family; community settings operated, funded or certified by DDS; residential programs that are not part 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 2014, 48.1% of the adults served by DDS resided in their own home, which includes people living independently or with their family. By 2015, this increased slightly to 48.6%.

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 2014, about 38.8% of adults served by DDS lived in a community residential program, and 2% 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 facilities[7], 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."[8]

Figure 7
Where People Live
Adult population served by DDS, 2015



In 2014, about 11% of adults served by DDS resided either in programs that are funded privately or by other agencies or in nursing homes. In 2015, this portion increased slightly to 11.6% 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.

REFERENCES

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

[2] 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.

[3] *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

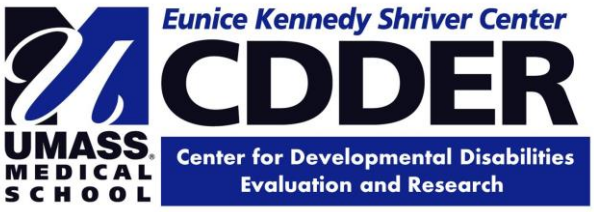
[4] https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Preadmission-Screening-and-Resident-Review-PASRR.html

[5] 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

[6] 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.

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

[8] The Community First Olmstead Plan. Massachusetts Executive Office of Health and Human Services, 2008.



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