

MA DDS Data Fact Sheet: Mortality Report Findings 2012–2013

Why does mortality data matter?

- The Massachusetts Department of Developmental Services (DDS) has a robust quality management and improvement system. Reviewing the causes and deaths of individuals supported by DDS is a component of this system. Data review helps to assure DDS that services are being provided effectively and safely and can highlight areas where system changes or prevention efforts are needed.

How many individuals served by DDS died in 2012–2013?

- 438 deaths occurred among adults eligible for DDS services in 2012. The **crude death rate** was 19.2 deaths per thousand people.
- 409 deaths occurred among adults eligible for DDS services in 2013. The **crude death rate** was 17.4 deaths per thousand people.

The **crude death rate** is a measure of how many people out of every thousand served by DDS died within the calendar year. It is determined by multiplying the number of people who died during the year by one thousand and dividing this number by the total number of people served by DDS during the same year.

How did 2012–2013 compare to previous years?

- The number of deaths for adults served by DDS was slightly lower in 2012 and 2013 as compared to 2011.
- The crude death rates in 2012 and 2013 were comparable to previous years. Between 2009 and 2011, the crude death rates were between 16.6 and 18.4. The 2012 crude death rate (19.2) was slightly higher and 2013 crude death rate (17.4) was just below the five-year period average (17.8).

Were there differences by age, gender or residential setting?

- As expected, younger age groups had lower crude death rates than older age groups. The crude death rate is substantially higher for all age groupings of people age 65 and older.
- Females had a higher average age at death than males (63.6 years compared to 61.5 years) and also experienced a higher crude death rate. This is due in part to the larger number of females in older age groupings.
- Crude death rates were higher for people in DDS community residences, DDS facilities, and nursing homes compared to people in their own or family homes, or Non-DDS residential programs. Generally, this is due to the relative age and health of the people living in each setting.
- Relationships between age, gender, and residential setting are consistent with previous years and data from other state intellectual/developmental disability (I/DD) systems.

What were common causes of death?

- Massachusetts DDS uses underlying causes of death in annual analyses.

“A cause of death is the morbid condition or disease process, abnormality, injury, or poisoning leading directly or indirectly to death. The underlying cause of death is the disease or injury which initiated the train of morbid events leading directly or indirectly to death or the circumstances of the accident or violence which produced the fatal injury.”

- The most common causes of death in 2013 were, from most to least common, cancer, heart disease, Alzheimer’s disease, aspiration pneumonia, influenza and pneumonia, septicemia, chronic lower respiratory disease, unintentional injury, congenital anomalies, and nephritis and other renal diseases.
- The most common causes of cancer deaths included lung cancer, colon cancer, and female breast cancer.
- While cancer and heart disease were also the leading causes of death in Massachusetts and the U.S., percent of deaths due to Alzheimer’s disease, and influenza and pneumonia were approximately three times higher in the DDS population. Septicemia and aspiration pneumonia were not leading causes of death in the general population.

What does this all mean?

- The data show that Alzheimer’s disease is a more common cause of death for people served by DDS, particularly for people with Down Syndrome, than for other people. Increased family and provider awareness about the prevalence of Alzheimer’s disease and earlier age of onset (as early as age 35) among people with I/DD may increase screening and planning for the changing needs of people with this disease. Increased awareness may also help in preventing complications from this disease and in addressing safety issues related to the symptoms of this disease.
- The data suggest that certain prevention strategies may be beneficial, including:
 - Promotion of breast and colorectal cancer screenings coupled with supports to increase the number of people who receive screenings. People with I/DD may experience have individualized accommodation needs for factors like special positioning needs or fears about screenings. They may also benefit from assistance in communicating with medical staff and assistance with environmental challenges like finding accessible screening centers that create barriers to getting screenings.
 - Family and provider awareness about the risk factors and prevention measures for aspiration pneumonia, an infection caused by food or fluid entering the lungs. This could be beneficial for reducing deaths due to aspiration pneumonia, septicemia, and chronic lower respiratory diseases.
 - Renewed effort to educate providers and families about early signs of infection in the I/DD population.