

People with Developmental Disabilities Have Much more Life to Live

Dalton Stevens

We use many phrases to express grief for death occurring before old age - *He was taken too soon. She was cut down in her prime. They had so much life left to live.* It just does not sit well with us when a family member or friend dies at a young age. Do these expressions apply to those with developmental disabilities (DD)? Premature death is common among adults with DD in the U.S. Despite this trend, health care providers, policymakers, and scholars have done little to address or understand the significantly shorter lifespans of people with DD.

Advances in modern medicine and public health that occurred since the early 1960s increased length of life for all Americans, including individuals with DD. Despite improvements, adults with DD continue to experience a death disadvantage, as they die 20-25 years earlier than adults in the general population.¹⁻² Highlighting the lack of appropriate attention to the lifespan of adults with DD, prior research has not differentiated whether this death disadvantage varies by type of DD - intellectual disability, cerebral palsy, Down syndrome, or other rare developmental disabilities. To better understand the DD death disadvantage, we document age at death for adults with various types of DD and compare these to age at death for adults without DD.³

An estimated 3.6 million noninstitutionalized adults in the U.S. have DD.⁴ Developmental disabilities are life-long conditions that manifest at birth or during early life through impairments in mobility, language, learning, self-care, and independent living.⁵ DD may be caused by a variety of factors, including but not limited to, genetics or fetal, natal, or post-natal injury.⁵ Intellectual disability, cerebral palsy, and Down syndrome are the most common types of DD, and may occur individually, simultaneously, or in conjunction with other types of DD. Our study is the first to differentiate age at death patterns for adults with various singular or co-occurring types of DD.

Adults with Developmental Disability (DD) Die Younger than Adults without DD

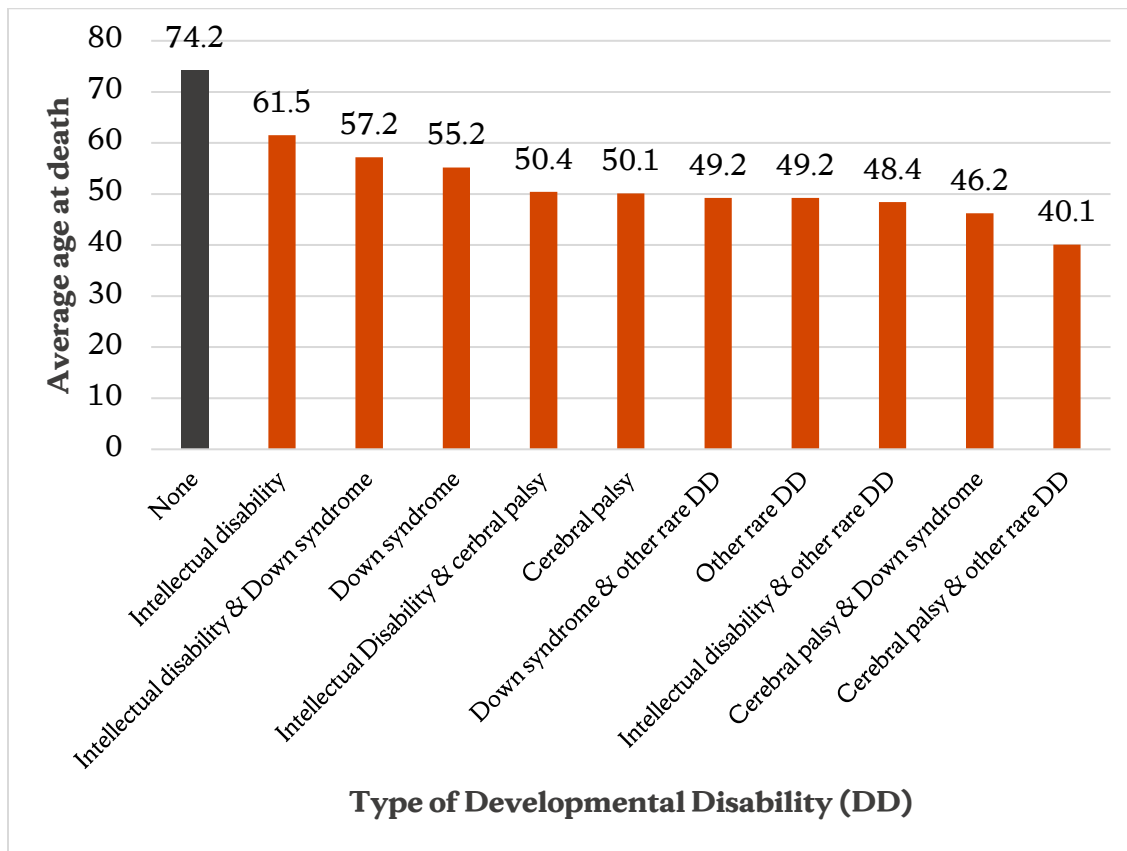
We used data from the 2012-2016 U.S. Multiple Cause-of-Death Mortality files to compare age at death for adults without a DD to adults with intellectual disability, Down syndrome, cerebral palsy,

KEY FINDINGS

- Adults with any type of development disability (DD) die an average of 23.5 years earlier than adults without developmental disability.
- The early death disadvantage is largest for those with cerebral palsy, other rare developmental disabilities, or co-occurring developmental disabilities, who die up to 34 years earlier than adults without DD.
- Individuals with intellectual disability die an average of 12.7 years earlier than those without DD.
- Adults with DD die at extremely higher rates between ages 18-39 compared to those without DD. 52% of adults with cerebral palsy and other rare DD died between ages 18-39, whereas only 4% of adults without DD died at these ages.

other rare DDs, and co-occurring DDs (e.g., co-occurring intellectual disability and cerebral palsy). Our results reveal clear distinctions in age at death by type of DD.

Figure 1. Adults with Developmental Disability Die at Much Younger Ages than those without DD



Data Source: U.S. Centers for Disease Control and Prevention Multiple Cause-of-Death Mortality Files, 2012-2016, (N=13,059,883 deaths); Chart: Dalton Stevens

In the U.S., on average, adults with any type of DD die 23.5 years earlier than adults without DD. However, the average age at death varies significantly by type of DD. For example, on the lower end of death disadvantage, adults with intellectual disability die 12.7 years earlier, on average, than adults without DD. In contrast, on the upper end of the death disadvantage, adults with cerebral palsy or other rare developmental disabilities, with or without a co-occurring DD, die an average of 23.8-34.1 years earlier than adults without DD. Adults with Down syndrome were in the middle of this range, dying between 17 and 28 years earlier, on average, than adults without DD, with the variation in the range depending on the presence of a co-occurring DD. Adults with the highest death disadvantage died between ages 18-39 at extremely high rates compared to those without DD. Most significantly, 52% of adults with cerebral palsy and other rare DD died between ages 18-39, whereas only 4% of adults without DD died at these ages. The age-at-death

Adults with the highest death disadvantage died between ages 18-39 at extremely high rates compared to those without DD.

difference between adults with and without DD are more pronounced for females than males with DD. However, these differences are due to the fact that females without DD live longer than males without DD, while females and males with DD survive to comparable ages. See the full article for results for biological sex and age comparisons across DD type.³

Public Health Implications

The lives of adults with DD are often cut short as this population dies, on average, over two decades earlier than adults without DD. However, the severity of the early death disadvantage depends on the type(s) of DD - those with intellectual disability or Down syndrome had the longest lives while those with cerebral palsy or other rare DD, especially if they had a co-occurring DD, had the shortest lives. These results show that it is not acceptable to simply report age-at-death differences for adults with DD as a singular group. Future research focused on understanding and reducing premature mortality among adults with DD must attend to differences in the early death disadvantage. This will provide accurate information for public health and preventive care efforts aimed at increasing longevity for individuals with DD. In addition, health care providers should consider age at death variability when assessing and treating populations with DD. Specifically, health care providers should be aware of increased mortality risk in early adulthood for those with cerebral palsy and other rare DD. People with DD *have much more life to live*. We must produce more attentive research, care, and supports in order to help them do so.

Data and Methods

We used the 2012-2016 U.S. Centers for Disease Control and Prevention Multiple Cause-of-Death Mortality files for adults aged 18 and older ($N = 13,059,883$). We rely on International Classification of Disease 10th Revision (ICD-10) to identify DD recorded on the compiled death certificates. For specific ICD-10 codes, see the published article.³ In total, 33,154 decedents had a DD recorded on their death certificate. Decedents with two or more developmental disabilities recorded on their death certificate make up the co-occurring groups presented in the figure. We calculated death disadvantage by finding the difference in mean age at death between adults without DD and those with each specific type of DD. See the journal article for full methodological description.

Endnotes

1. Lauer, E., and McCallion P. (2015). Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *Journal of Applied Research in Intellectual Disabilities* 28:394-405.
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