Lerner Center
FOR PUBLIC HEALTH PROMOTION
Maxwell | Syracuse University

RESEARCH BRIEF
Issue Number 2
February 26, 2019

What are we hiding? Preventable causes of death are not accurately counted for adults with intellectual disability

Scott D. Landes

KEY FINDINGS

- Identifying developmental disabilities as the underlying cause of death on death certificates hides high rates of preventable choking deaths.
- CDC guidelines for completing death certificates allow the practice of inaccurately identifying developmental disabilities as cause of death and must be changed.
- Developmental disabilities should be recorded only as a contributing cause of death, not the primary cause.

Imagine you are the sibling of an adult with a developmental disability named Rachel. Rachel always seemed to have trouble swallowing her food - what her physician referred to as 'dysphagia'. Last week she choked while eating dinner, resulting in a severe case of pneumonia from which the intensive care unit (ICU) doctor thinks she will not recover. You accompany your parents by Rachel's hospital bed and reflect on her life, on the meaning she brought to each of you and others she met. Despite the challenges she faced in learning and socializing, and the fact that people often could not look beyond her disability and really see Rachel, she was resilient, and lived a full and meaningful life.

After she is gone, you take charge of obtaining her death certificate and filing for her life insurance. When the death certificate arrives, you browse the document to make sure it is accurate. It correctly states that Rachel choked and developed pneumonia. But it lists her *underlying cause of death*, the condition that the doctor identified as "the disease or injury that started the process of events that led to her death" (i.e., the primary cause of death), as 'Mental Retardation.' You are confused. Surely, this is a mistake. First, no one uses that offensive term anymore - they use 'intellectual disability'. Second, Rachel died because she choked on her food and developed pneumonia, not because of her disability. A disability does not cause death.

It is not a mistake. It is the last insult from a world that often refuses to look beyond a person's disability to see who they really are, or in this case, what really caused their death.

Unfortunately, it is common, occurring in 48.5% of deaths among adults with a developmental disability in the U.S.[1] This is a cruel insult to families who have to endure a final dismissal of their loved one. It also has detrimental consequences for those working to improve the health of adults with a developmental disability. Beyond the practical purposes they serve for funeral arrangements and insurance claims, death certificates are intended to provide valuable data that allows researchers to better understand *why* people are dying. To do so, we need to understand what causes persons with disabilities to die. Because close to half of the death certificates for persons with developmental disabilities erroneously record their disability as their primary cause of death, we do not have this information readily available.

Revealing Actual Causes of Death

In our research,[1] we analyzed the death certificates of 33,154 adults with a developmental disability who died between 2012 and 2016 to determine how many inaccuracies there are in cause of death reporting for people with a developmental disability. What we found was disturbing.

Properly revising these death certificates to identify the true primary cause of death reveals that a much higher percentage of adults with a developmental disability died from respiratory disease (26.2% when revised, as opposed to 10.5%), heart disease (17.4% when revised, as opposed to 12.2%) and external causes (6.0% when revised, as opposed to 2.6%) than previously thought. When we dug deeper, we found that the primary respiratory diseases killing these adults were 'Pneumonitis due to inhalation of food/vomit' (9.7%) and 'Pneumonia' (8.4%). The primary external cause was 'Accidental inhalation and ingestion of food or other objects causing obstruction of the respiratory tract' (3.7%). Thus, recording the death as being caused by a disability, in the presence of more direct causes of death, hides an unacceptably high rate of preventable choking deaths among adults with developmental disability.

The most disturbing part of this story may be that the organization that provides direction on how to complete a death certificate allows this practice to continue. In the U.S., the Centers for Disease Control and Prevention (CDC) provides guidelines for completing death certificates based on suggestions provided by the World Health Organization (WHO). The CDC's guidelines for completing death certificates specifies that the direct cause of death is to be listed in Part I of the death certificate, while Part II is supposed to include other diagnoses the decedent had at the time of death, that contributed to, but did not directly cause death. The CDC guidelines also specify which diagnoses are allowed to be listed as a cause of death.[2] Although developmental disabilities are not diseases or injuries that can initiate the causal sequence of events leading to death, the CDC allows, and at times even encourages, them to be listed as the underlying cause of death in Part I. In doing so, it allows individuals who complete the death certificate (e.g., medical examiner, coroner, attending physician) to continue recording developmental disabilities as a cause of death. As the cause of death is the primary measure used in evaluating population mortality trends, this practice hides a high percentage of preventable deaths among adults with developmental disability.

How Can we Fix This?

Researchers concerned about making sure we have accurate mortality data for adults with developmental disability agree on a simple solution to this problem. Organizations that provide guidelines for death certificate completion, such as the CDC, should mandate that developmental disabilities should not be listed in Part I of the death certificate, but should be recorded in Part II only.[1,3-5] Doing so would ensure that the death certificates for adults with a developmental disability record their actual cause of death, instead of inaccurately recording that they died from a disability. This would ensure more reliable data on mortality trends for this population, which would increase the chance of identifying and addressing health risks for those currently living with these disabilities. In turn, this may help to reduce preventable deaths among this population and extend their lives. For the families of adults such as Rachel, we would prevent an unnecessary and cruel last act of overlooking their loved one because of their disability. Individuals with developmental disability and their families have experienced mistreatment for way too long, including in the way we record their deaths. It is time for this to change.

Data

Death certificate data are from the CDC's 2012-2016 Multiple Cause of Death Files. We pooled 5 years of data in order to have a sufficient number of cases for each type of developmental disability in our analysis. We analyzed the death certificates for 33,154 adults with a developmental disability who died in the U.S. between 2012 and 2016: 7,901 with intellectual disability, 11,895 with cerebral palsy, 9,114 with Down syndrome, 2,479 with other developmental disabilities, and 1,765 with multiple developmental disabilities. Full methodological details, including the specific ICD-10 codes utilized to identify a developmental disability and the process used to revise the death certificates, as well as results for each developmental disability group, are presented in Landes et al., (2019).[1]

References

1. Landes, S. D., Stevens, J. D., & Turk, M. A. (2019). The obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: A cross-sectional study utilizing U.S. Mortality data from 2012 to 2016. *BMJ Open, 9:e026614*. https://bmjopen.bmj.com/content/9/2/e026614.
2. National Center for Health Statistics. (2017). Part 2 - instructions for classifying the underlying and multiple causes of death. Retrieved from https://www.cdc.gov/nchs/nvss/instruction_manuals.htm
3. Landes, S. D., & Peek, C. W. (2013). Death by mental retardation? The influence of ambiguity on death certificate coding error for adults with intellectual disability. *Journal of Intellectual Disability Research*, 57(12), 1183-1190.
4. Stirton, F. D., & Heslop, P. (2018). Medical certificates of cause of death for people with intellectual disabilities: A systematic literature review. *Journal of Applied Research in Intellectual Disabilities*, *31*(5), 659-668.
5. Tyrer, F., & McGrother, C. (2009). Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of Intellectual Disability Research*, 53(11), 898-904.

About the Author

Scott D. Landes is an Assistant Professor of Sociology, Faculty Associate at the Aging Studies Institute, and Faculty Research Affiliate at the Lerner Center for Public Health Promotion in the Maxwell School of Citizenship and Public Affairs at Syracuse University (sdlandes@maxwell.syr.edu).