



# Mortality trends among adults with intellectual and/or developmental disability

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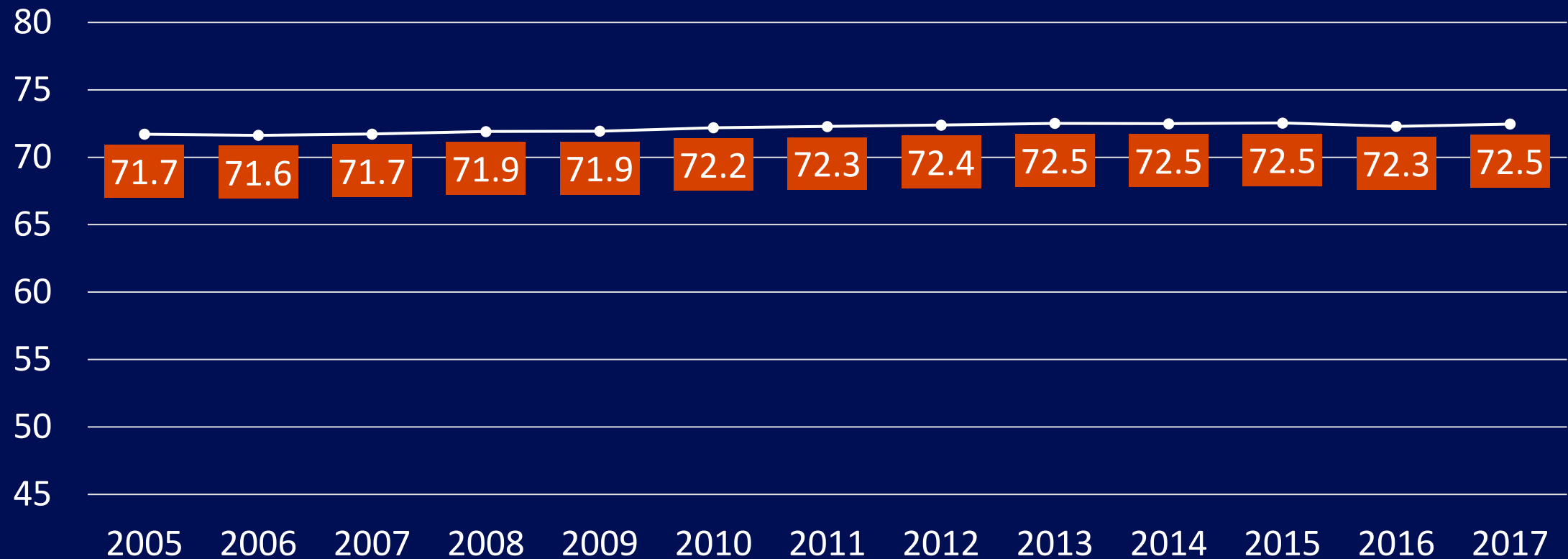
# Age at death patterns

- 1931-1935: 15-22 years (Carter and Jancar 1983; Janicki et al. 1999)
- 1980s – 1990s: increased from late 50s to mid 60s
- Attributed to:
  - Improvements in health
  - Deinstitutionalization
  - Better access to health care (Boyle et al. 2011; Lauer et al. 2015)
- Questions: continued improvement? All disability statuses?

# Age at death patterns by disability status: 2005-2017

Landes, Scott D., Katherine E. McDonald, Janet M. Wilmoth and Erika Carter Grosso. 2021. "Evidence of Continued Reduction in the Age-at-Death Disparity between Adults with and without Intellectual and/or Developmental Disabilities." *Journal of Applied Research in Intellectual Disabilities* 34(3):916-20. doi: 10.1111/jar.12840.

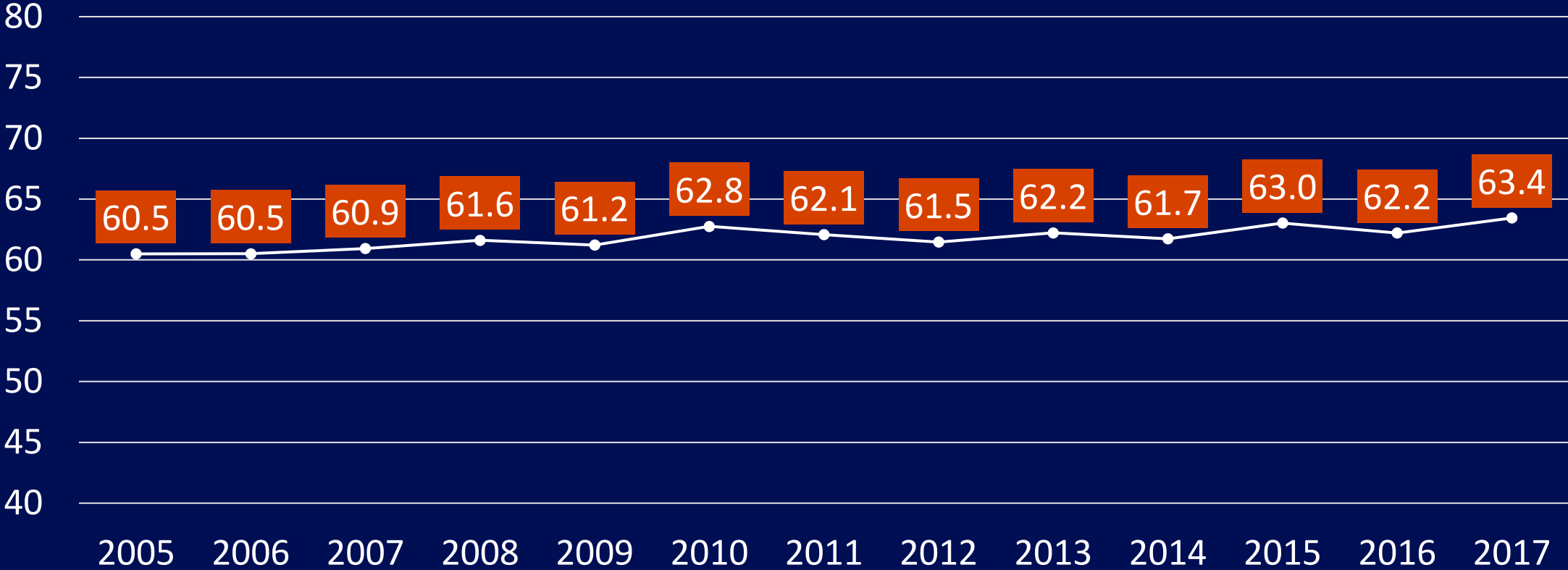
## No intellectual or developmental disabilities



# Age at death patterns by disability status: 2005-2017

Landes, Scott D., Katherine E. McDonald, Janet M. Wilmoth and Erika Carter Grosso. 2021. "Evidence of Continued Reduction in the Age-at-Death Disparity between Adults with and without Intellectual and/or Developmental Disabilities." *Journal of Applied Research in Intellectual Disabilities* 34(3):916-20. doi: 10.1111/jar.12840.

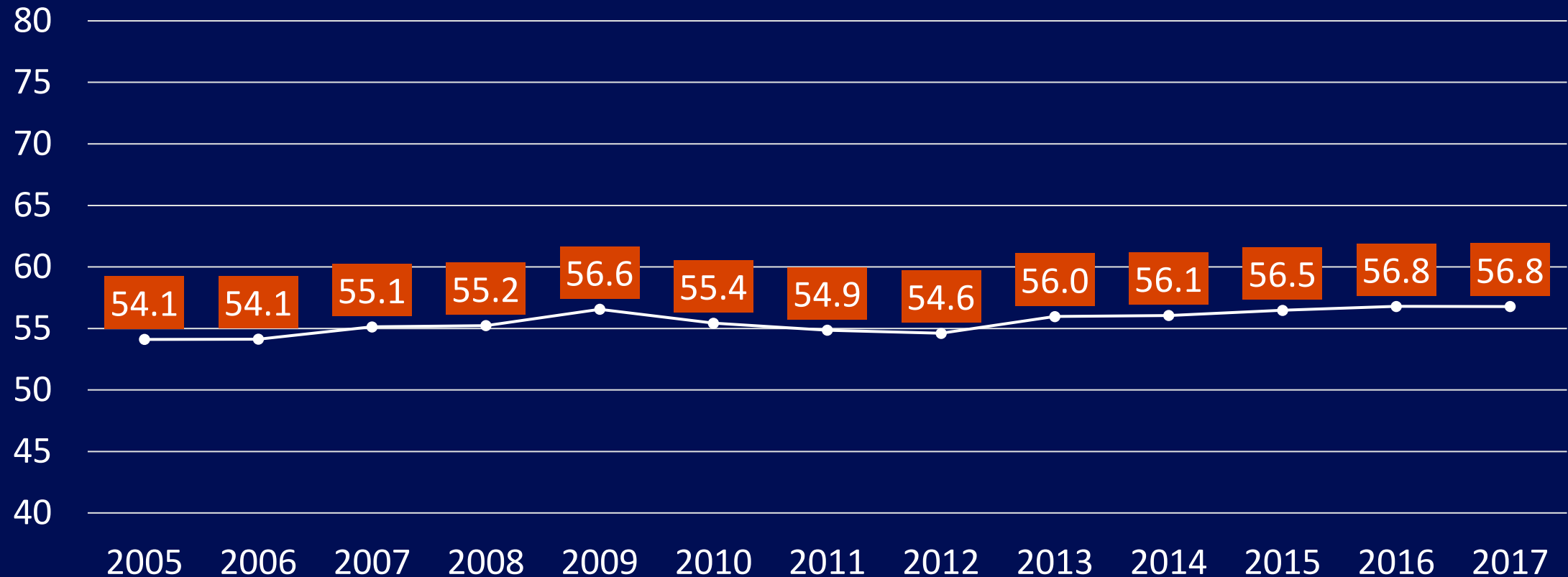
Intellectual disability (11.2 to 9.1y)



# Age at death patterns by disability status: 2005-2017

Landes, Scott D., Katherine E. McDonald, Janet M. Wilmoth and Erika Carter Grosso. 2021. "Evidence of Continued Reduction in the Age-at-Death Disparity between Adults with and without Intellectual and/or Developmental Disabilities." *Journal of Applied Research in Intellectual Disabilities* 34(3):916-20. doi: 10.1111/jar.12840.

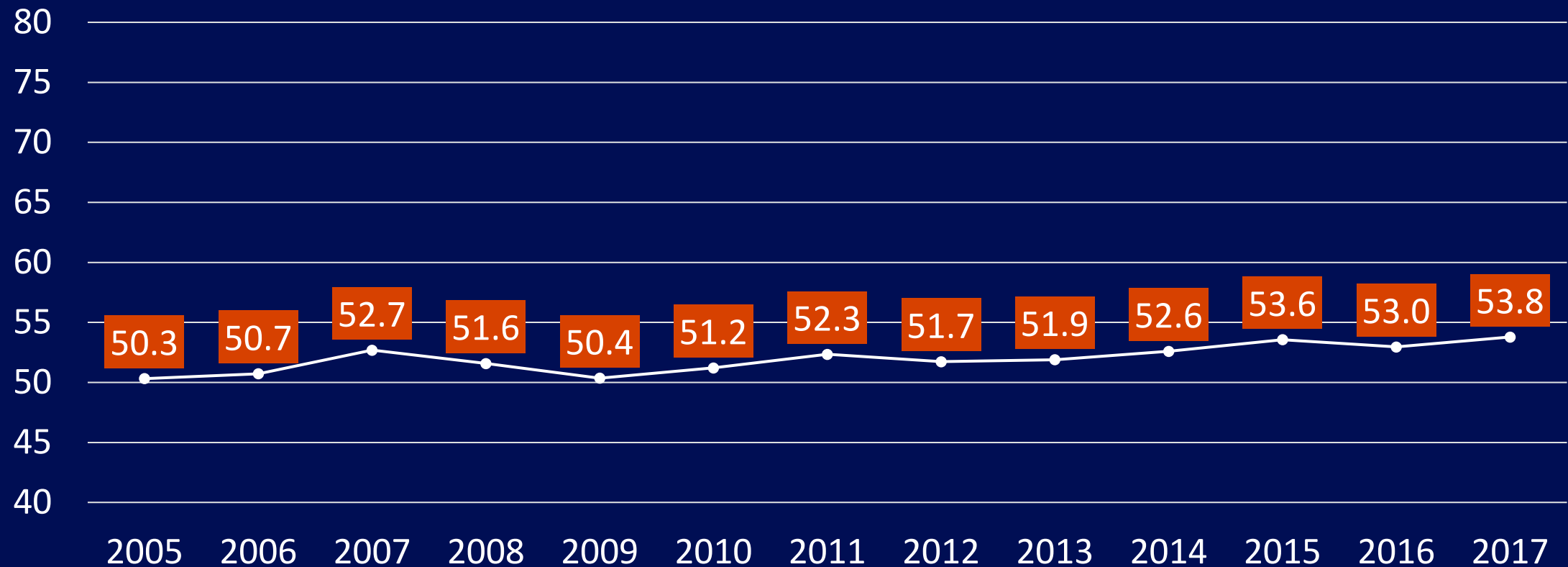
## Down syndrome (17.6 to 15.7y)



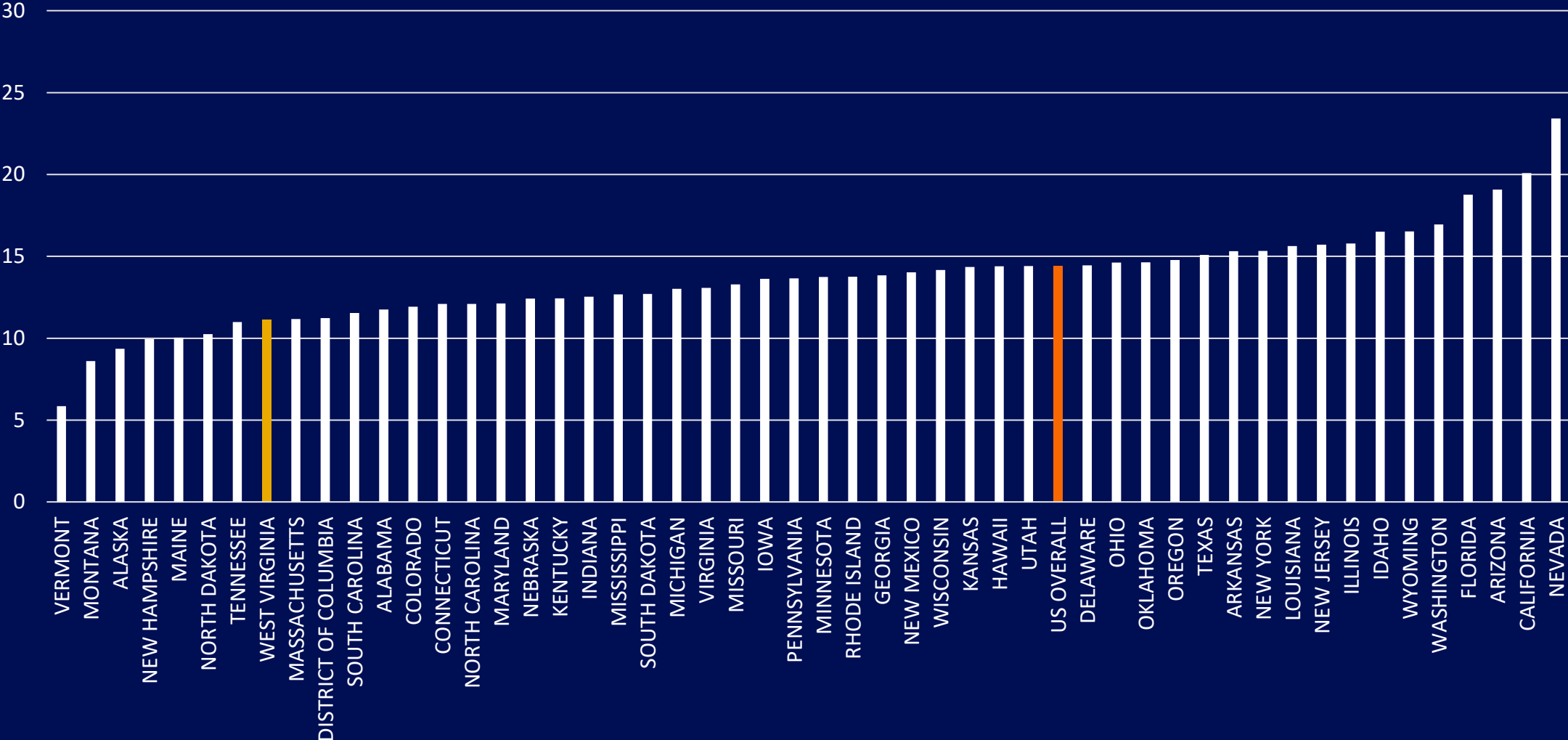
# Age at death patterns by disability status: 2005-2017

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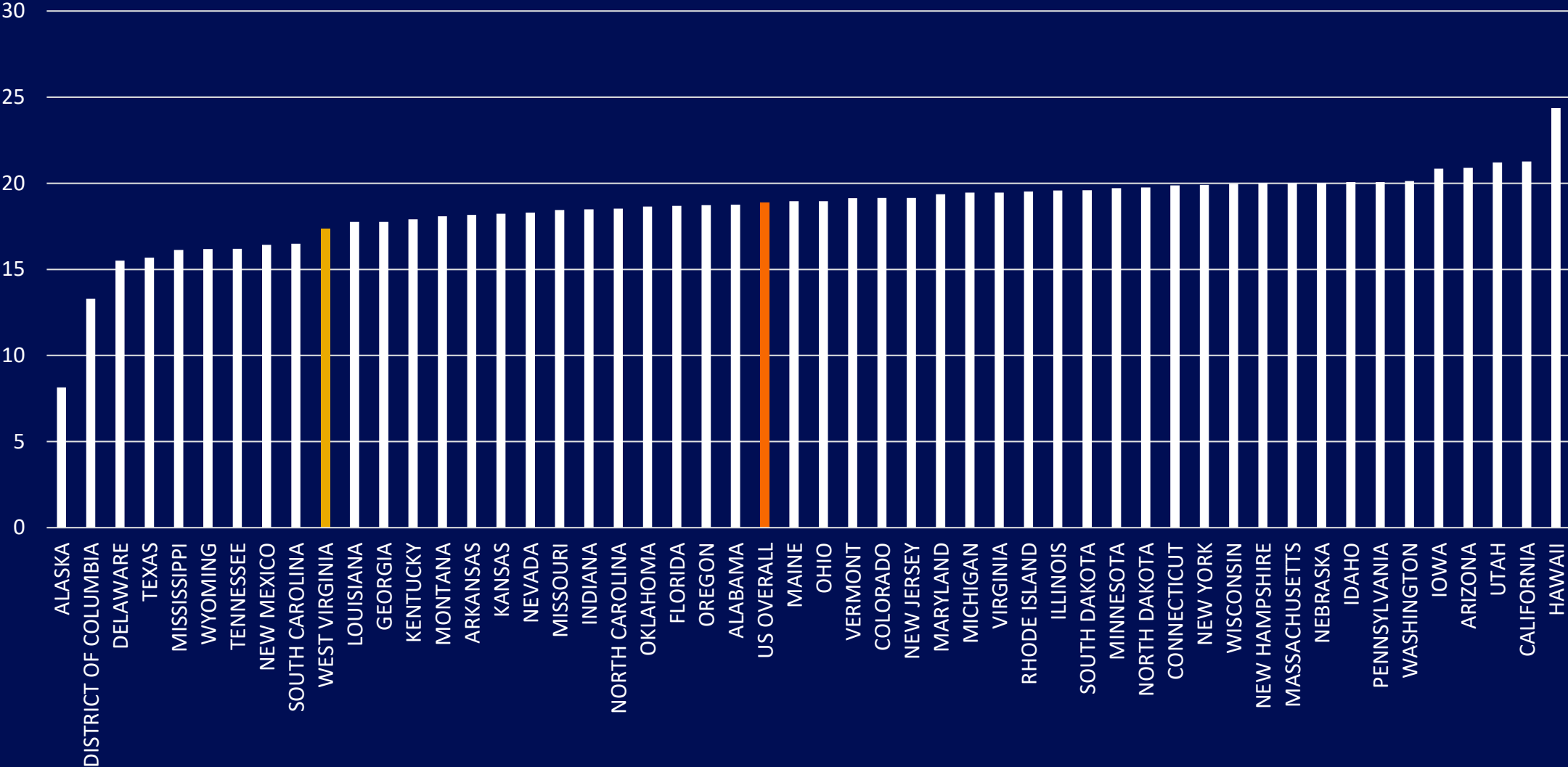
## Cerebral palsy (21.4 to 18.7y)



# Age at death disparity by state – intellectual disability



# Age at death disparity by state – Down syndrome





# Age at death disparity by state – cerebral palsy



# Why does the age of death disparity still exist?

- Causes of death
  - Underlying cause of death (UCOD)
  - Focus of public health efforts aimed at preventing premature mortality
  - Better understanding of disease burden
  - Similar or different for people with/without IDD?

# Inaccurate reporting

- UCOD is supposed to be a disease or injury that started the sequence of events leading to death
- Intellectual and developmental disabilities are not diseases or injury, but disabilities
- In general, should not be reported at the UCOD
- Doing so obscures our understanding of cause of death patterns for this population

# Frequency of inaccurate reporting

Landes, Scott D., J. Dalton Stevens and Margaret A. Turk. 2019. "Obscuring Effect of Coding Developmental Disability as the Underlying Cause of Death on Mortality Trends for Adults with Developmental Disability: A Cross-Sectional Study Using Us Mortality Data from 2012 to 2016." *BMJ Open* 9:e026614:1-10. doi: 10.1136/bmjopen-2018-026614.

- Intellectual disability – 25.9%
- Down syndrome – 59.0%
- Cerebral palsy – 59.5%
- Obscures higher rates of death from:
  - Respiratory diseases such as pneumonia
  - External causes of death such as accidental choking

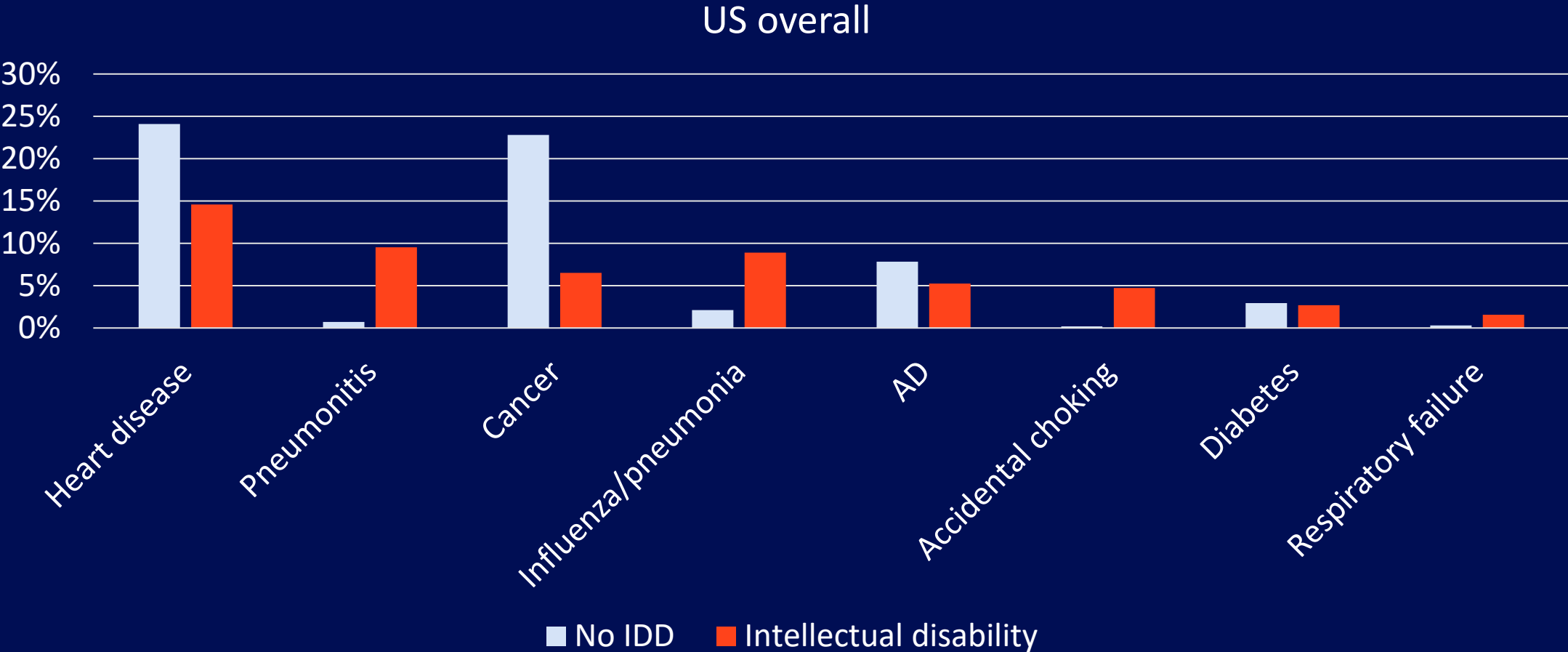
# Predictors of inaccurate reporting

Landes, Scott D., Margaret A. Turk and Erin Bisesti. 2021. "Uncertainty and the Reporting of Intellectual Disability on Death Certificates: A Cross-Sectional Study of Us Mortality Data from 2005 to 2017." *BMJ Open* 11(1):e045360. doi: 10.1136/bmjopen-2020-045360.

- Clinical uncertainty – less information on comorbidities reported on the death certificate
- False equivalence – incorrectly attributing diseases to aspects of disability, e.g. seizure disorders, AD for Down syndrome
- Racial/ethnic disparities for adults with Down syndrome and cerebral palsy
  
- Solution – DC corrections

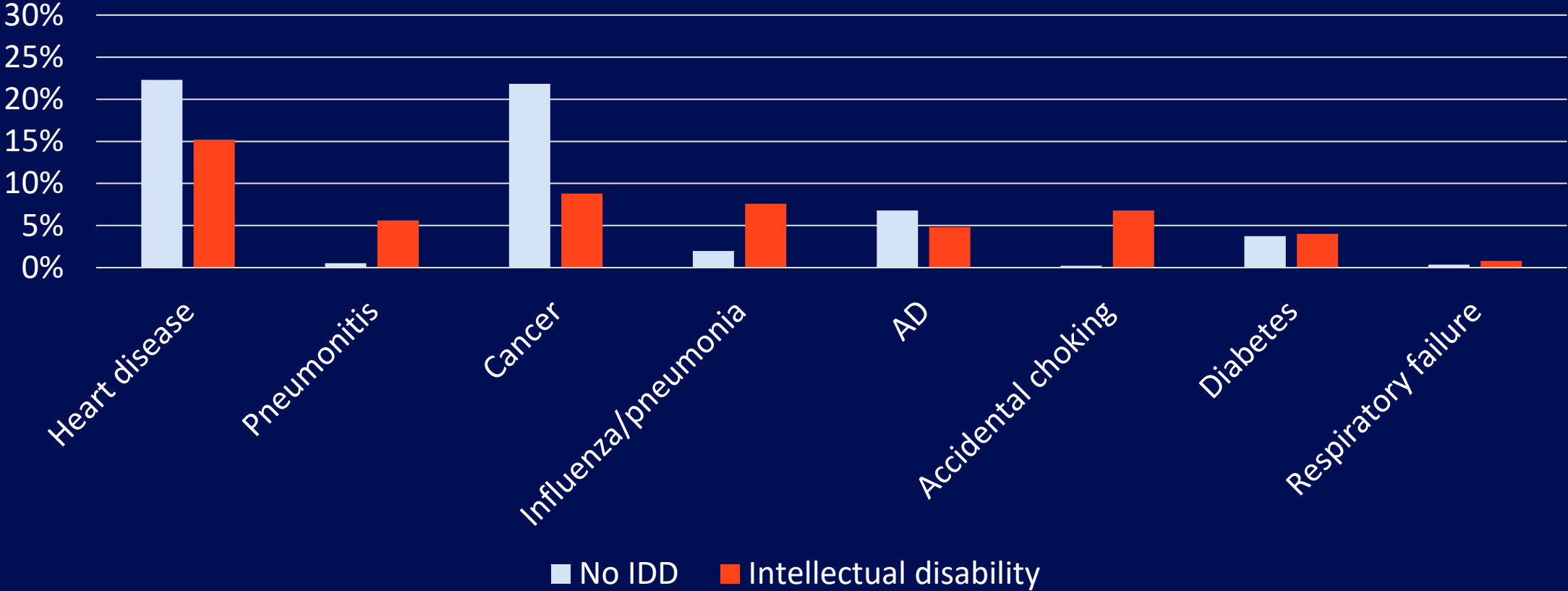
# Causes of death for adult with intellectual disability

Landes, Scott D., J. Dalton Stevens and Margaret A. Turk. 2020. "Cause of Death in Adults with Intellectual Disability in the United States." *Journal of Intellectual Disability Research* 65(1):47-59. doi: 10.1111/jir.12790.



# Causes of death for adult with intellectual disability

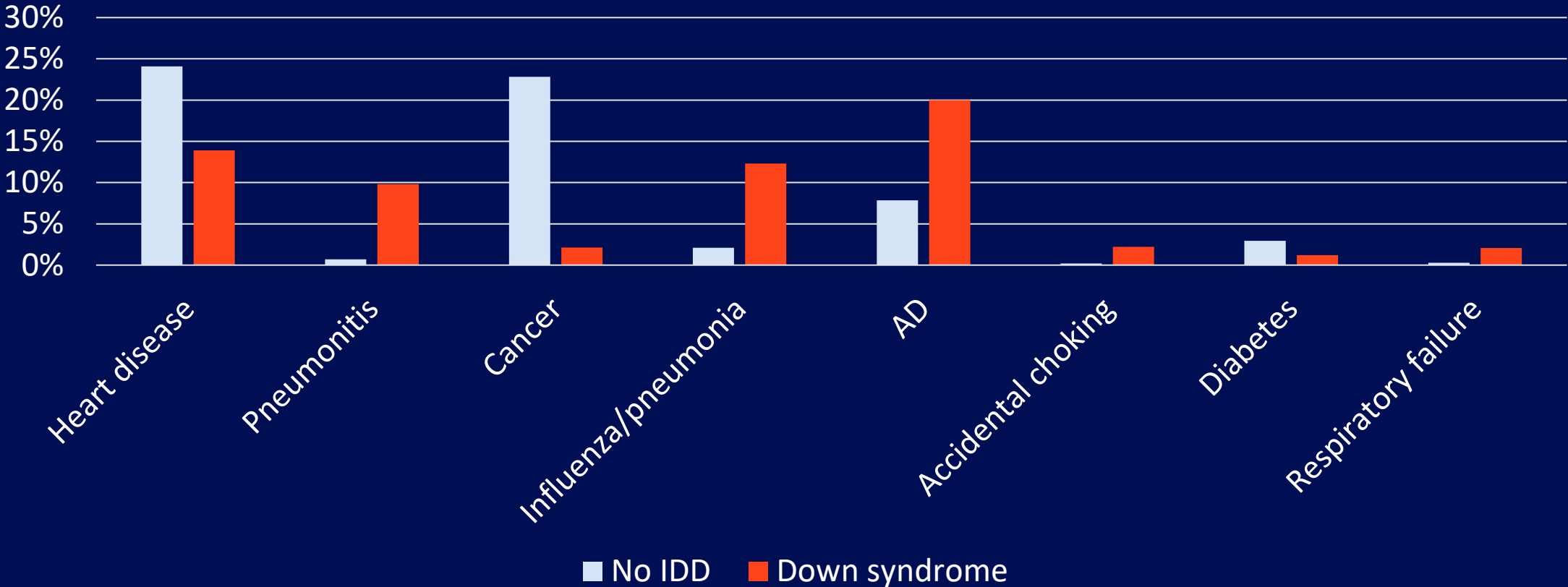
West Virginia



# Causes of death for adult with Down syndrome

Landes, Scott D., J. Dalton Stevens and Margaret A. Turk. 2020. "Cause of Death in Adults with Down Syndrome in the US." *Disability and Health Journal* 13(4):1-9. doi: 10.1016/j.dhjo.2020.100947.

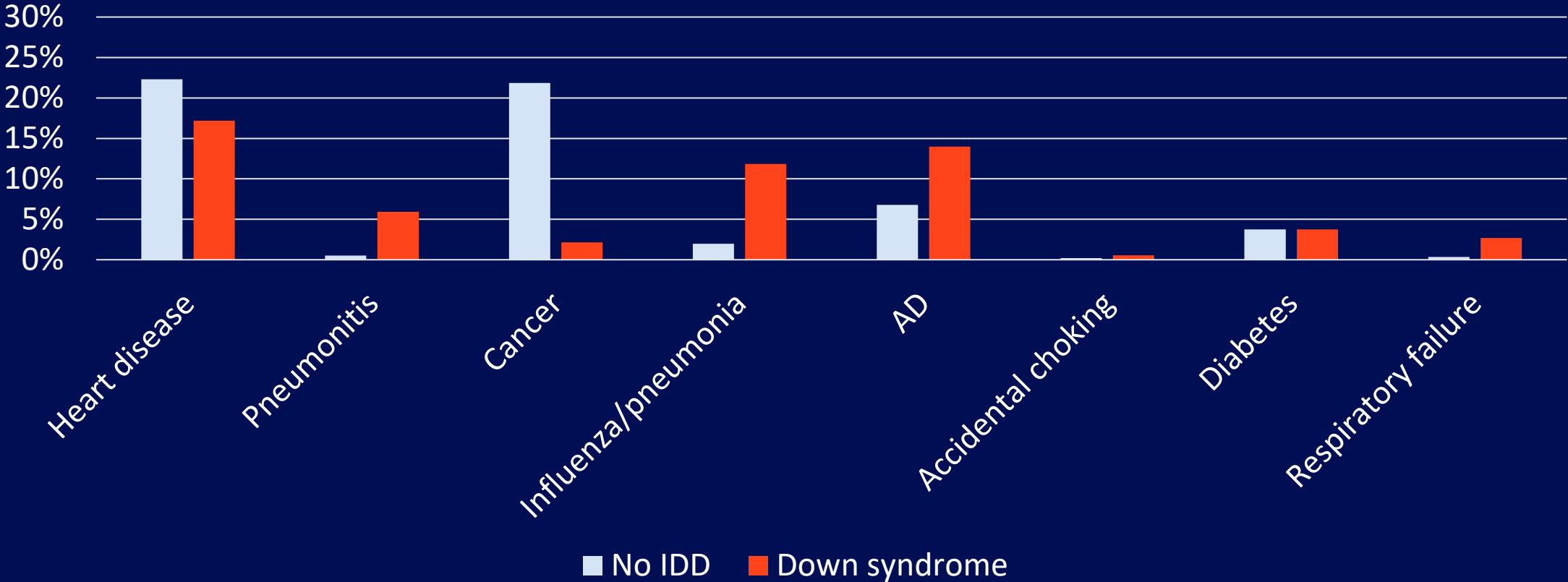
US overall





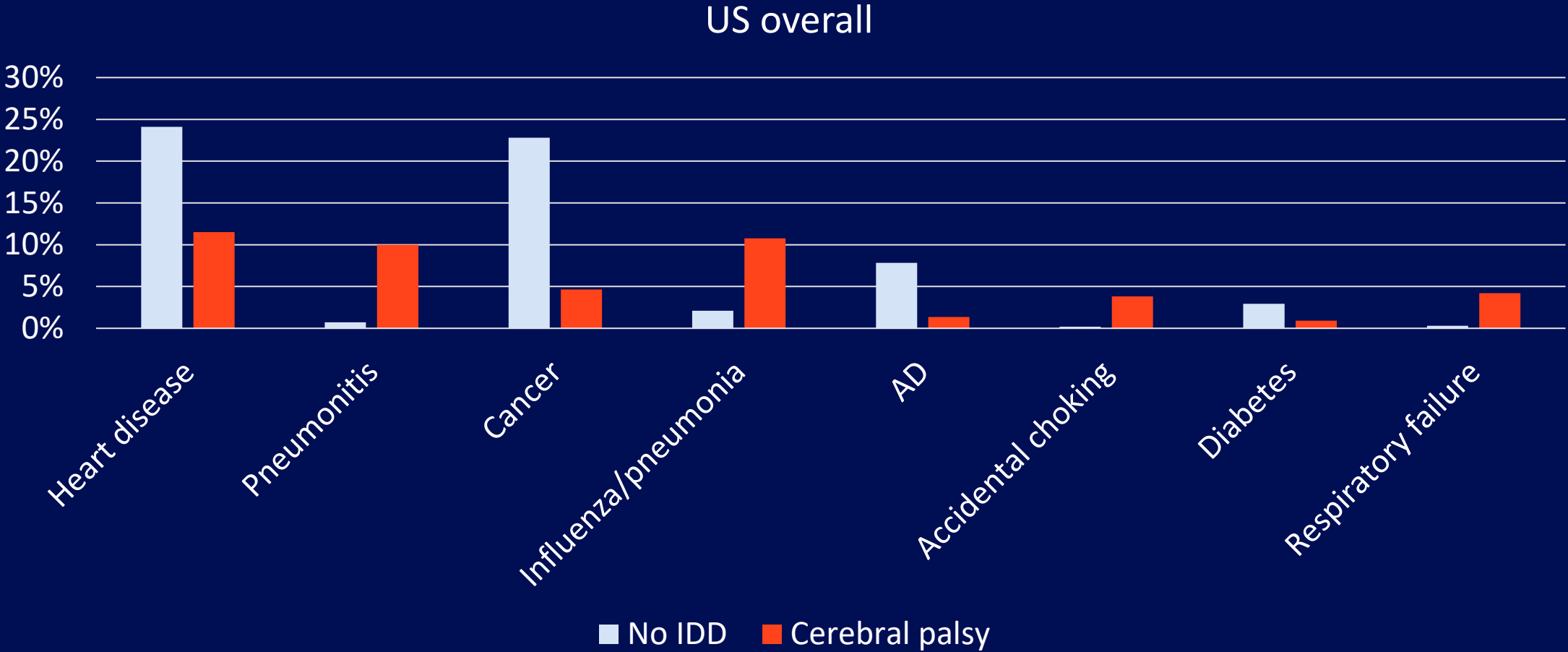
# Causes of death for adult with Down syndrome

West Virginia



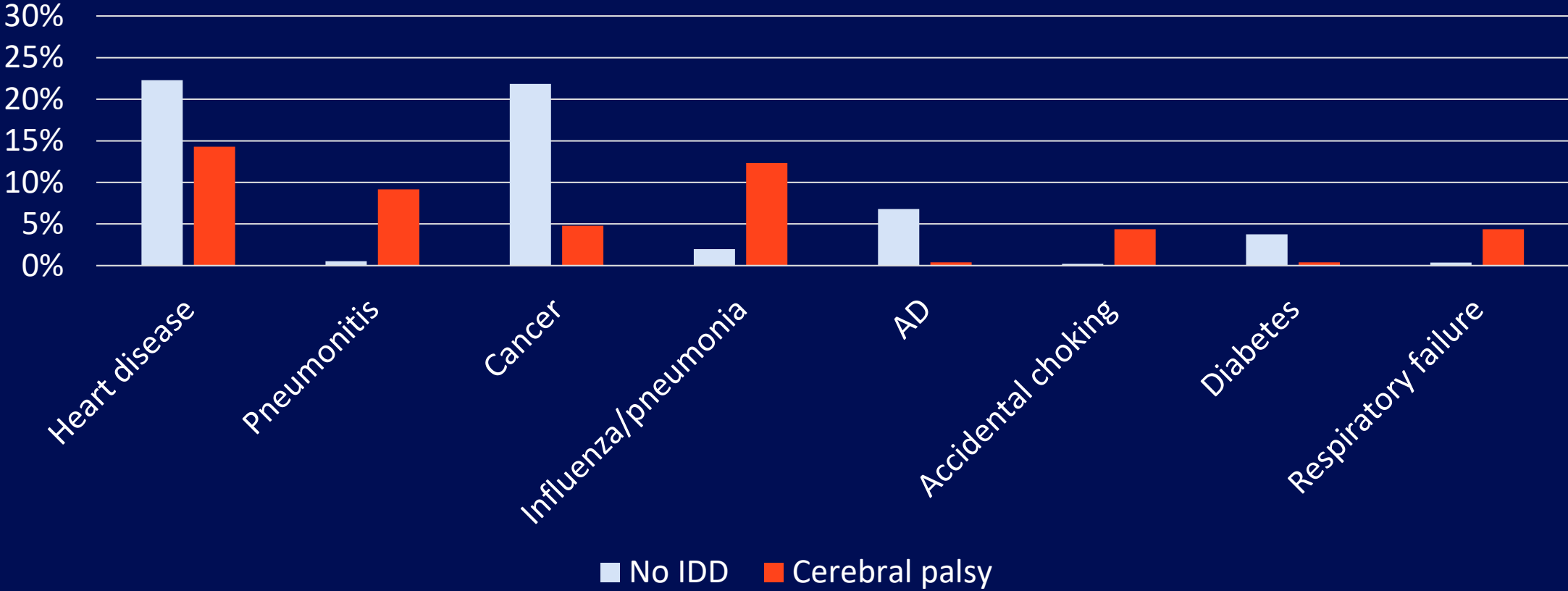
# Causes of death for adult with cerebral palsy

Stevens, J. Dalton, Margaret A. Turk and Scott D. Landes. 2021. "Cause of Death Trends among Adults with and without Cerebral Palsy in the United States, 2013-2017." *Annals of Physical and Rehabilitation Medicine*. doi: 10.1016/j.rehab.2021.101553.



# Causes of death for adult with cerebral palsy

West Virginia



# Summary

- Improvements, but persisting disparity in age at death
- Respiratory deaths – pneumonia, pneumonitis
- External cause of death – accidental choking
- All point to need to emphasize proper care for aphagia/swallowing problems
- Next steps
  - AD and Down syndrome
  - Demographic differences differences



## Contact information

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