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## Recommendations for Accurately Reporting Intellectual and Developmental Disability on Death Certificates

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### INTRODUCTION

Despite critical advances in medical technology and an increased emphasis on improving access to medical care for all individuals over the past 25 years, adults with intellectual and developmental disabilities still die, on average, 15–20 years earlier than their peers in the general population.<sup>1,2</sup> These types of disability typically manifest before age 18 years; are lifelong conditions; and involve physical, learning, language, or behavioral impairments.<sup>3</sup> Table 1 provide a list of types of intellectual and developmental disabilities and corresponding ICD-10 codes. As with any other group, public health efforts aimed at reducing premature mortality among individuals with intellectual and developmental disability are reliant on accurate cause of death information.<sup>4</sup> However, the way in which intellectual and developmental disabilities are currently reported on U.S. death certificates prevents attainment of a precise understanding of cause of death trends among this population.

### INACCURATE REPORTING OF INTELLECTUAL AND DEVELOPMENTAL DISABILITY

For nearly half (48.5%) of adult decedents who had an intellectual or developmental disability identified on their death certificate in the U.S. between 2012 and 2016, their disability was reported as their underlying cause of death.<sup>5</sup> Because it conflates disability and health, the practice of reporting an intellectual or developmental disability as the underlying cause of death is recognized as imprecise at best, and harmful to public health

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efforts at worst.<sup>5,6</sup> As the WHO instructs, disability, including intellectual and developmental disability, is —not a health problemll but a —complex phenomenonll involving interactions between bodily impairments and societal structures.<sup>7</sup> As disability does not fit the Center for Disease Control and Prevention’s (CDC’s) definition of an underlying cause of death—a —”disease or injury than initiated the train of morbid events leading directly to death,”<sup>8</sup>—and is not fatal, those researching mortality trends among this population advise that it typically should not be reported as the underlying cause of death.<sup>5,9</sup> A recent study clearly demonstrates that the excessive practice of reporting an intellectual or developmental disability as the underlying cause of death limits the understanding of actual mortality risk factors for this population by —obscuringll higher rates of death from possibly preventable medical causes such as pneumonitis or choking for adults with all types of developmental disability, as well as dementia and Alzheimer disease-related deaths among adults with Down syndrome.<sup>5</sup>

## INTELLECTUAL AND DEVELOPMENTAL DISABILITY AS CONTRIBUTING CAUSE OF DEATH

If intellectual and developmental disabilities should not typically be reported as the underlying cause of death, how should these disabilities be reported on the death certificate? As they are disabilities, and not diseases or injuries, they should only rarely be included in Part I of the death certificate. It is justifiable to do so if the clinical history of the decedent provides ample evidence that the disability was associated with a particular genetic condition that initiated the sequence of events leading to death. However, in these uncommon cases, the clinician should carefully document the full sequence of events leading from the underlying cause of death to the immediate cause of death.<sup>10</sup> More commonly, intellectual and developmental disabilities should be reported in Part II of the death certificate.<sup>5</sup> Per CDC instructions, Part II of the death certificate is intended to include all —”other important diseases or conditions that were present at the time of death and that may have contributed to death.”<sup>8</sup> It is important to note that the guidelines provided by CDC for Part II are broader than those for the underlying cause of death as they allow for the inclusion of diseases and conditions that may have contributed to death.

Certain intellectual and developmental disabilities, such as cerebral palsy or Down syndrome, have clear associations with specific comorbid diseases,<sup>11,12</sup> making the logic of reporting these disabilities as a contributing cause of death in Part II of the death certificate more apparent. However, owing to the dearth of disability education in medical school and other professionals’ curricula,<sup>13</sup> those completing the death certificates may not be aware of those associations. This can result in either diagnostic overshadowing, when an intellectual or developmental disability is inaccurately reported as the underlying cause of death,<sup>14</sup> or under-reporting, when the intellectual or developmental disability directly or indirectly contributed to the death but is not included on the death certificate at all.

For other types of intellectual and developmental disability, such as when a decedent had an intellectual disability that was not resultant of any type of genetic disorder or physiological impairment, the association between the disability and sequence of events leading to death

may not be as readily apparent to the certifier. For these cases, it is important to recognize the ways in which non-genetic or non-physiological factors that often accompany the disability contribute to death. Particularly for adults with intellectual and developmental disability, poorer health and premature mortality are often a result of a toxic combination of lower SES (poverty, reduced education, underemployment), increased social isolation and prevalence of abuse, substandard care, lack of access to proper medical care, unhealthy living environments, lack of understanding of the consequences of positive and negative health behaviors, polypharmacy, and delayed or underdiagnosis of primary health conditions.<sup>15–18</sup> As a result of these detrimental social circumstances, in most instances an individual's intellectual or developmental disability is very likely to at least indirectly contribute to their death. Thus, any intellectual or developmental disability, when known, should be given serious consideration by the person certifying the death certificate for inclusion as a contributing cause of death in Part II of the death certificate.

There are rare occasions in which there may be no readily apparent justification to report the intellectual or developmental disability on the death certificate. Purely accidental deaths, such as death due to a motor vehicle accident, may present this type of scenario. Though plausible for the certifier to make the determination to not report the intellectual or developmental disability on the death certificate at all in these cases, in order to do so, it should be unequivocal that the developmental disability did not, either directly or indirectly, contribute to the death.

## **ACCURATE REPORTING OF INTELLECTUAL AND DEVELOPMENTAL DISABILITY**

To address the problem of inaccurate reporting of intellectual and developmental disabilities on death certificate comprehensively, it may require increased specificity in the standardized death certificate coding rules to address situations where intellectual or developmental disability is reported incorrectly as the underlying cause of death. Ideally, this would be addressed by the WHO, as this is the body that publishes instructions for completing death certificates that are utilized by a large portion of the global community. However, it would also be possible, and helpful, for agencies spearheading public health efforts in individual countries, such as CDC in the U.S., to enact these death certificate coding rule changes.

In addition to these needed changes to death certificate coding rules, it is also crucial for those certifying death certificates to accurately report the intellectual and developmental disability at the time of death. Accurate reporting of intellectual and developmental disability on the death certificate involves a 2-step process. In the first step, the individual certifying the death certificate reports the actual disease or injury that initiated the causal death sequence as the underlying cause of death in Part I of the death certificate. In the second step, the individual certifying the death certificate reports the intellectual or developmental disability, if it is reasonable to think that it may have contributed to the death, in Part II of the death certificate.

If this 2-step process were observed by those certifying death certificates, a large majority, if not all, of the inaccurate reporting of intellectual and developmental disabilities as

underlying cause of death would no longer occur. In the event that a correction rule is enacted at the coding stage by the WHO or CDC, it would serve to identify and recode any of the remaining certifier-level errors in reporting that resulted from not following this 2-step process. Until these changes are enacted, the authors highly recommend that researchers analyzing cause of death trends for individuals with intellectual and developmental disability identify death certificates that inaccurately report intellectual and developmental disability as the underlying cause of death, and perform the correction by rule to accurately identify the underlying cause of death to the extent possible utilizing multiple cause of death information reported on the death certificate.<sup>5</sup>

An example illustrates this proposed 2-step process for the certifier. The case involves a female decedent with cerebral palsy who developed pneumonia that led to acute kidney failure, cardiac arrest, and death at age 68 years. As is depicted in Column 1 of Table 2, a certifier may assume people with cerebral palsy are likely to die early because of their disability, and inaccurately report cerebral palsy as the underlying cause of death in Part I without regard to the actual medical condition that initiated the sequence of events leading to death—pneumonia. Or, as is depicted in Column 2 of Table 2, if the developmental disability's indirect contribution to the death is not appreciated, the certifier may neglect to report it as a contributing cause of death in Part II. Both of these scenarios represent inaccurate reporting of the cerebral palsy on the death certificate. Accurate reporting is depicted in Column 3 of Table 2. The first step results in the reporting pneumonia as the underlying cause of death. The second step results in reporting cerebral palsy as a contributing cause of death in Part II of the death certificate.

## CONCLUSIONS

The authors acknowledge that this proposed 2-step process would not guarantee information on the deaths of all individuals with intellectual and developmental disability. There may be rare occasions when a certifier decides to not report the intellectual or developmental disability, or instances when the certifier has no awareness of the disability. However, limiting the frequency in which these disabilities are reported inaccurately as the underlying cause of death and increasing the frequency in which they are accurately reported in Part II of the death certificate would vastly improve the reliability of mortality trends for this population. Based upon findings from an earlier study, it is likely that improving the accuracy of death certificate reporting for individuals with intellectual and developmental disability will reveal higher rates of death from acute respiratory diseases such as pneumonia, and highly preventable causes of death such as pneumonitis and accidental choking due to inhalation of food or vomit.<sup>5</sup> As a result, public health and preventive care efforts would be informed by a more accurate understanding of mortality trends among individuals with intellectual and developmental disability, and would have a higher likelihood of success in reducing premature mortality among this population.

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## REFERENCES

1. Landes SD, Stevens JD, Turk MA. Heterogeneity in age at death for adults with developmental disability. *J Intellect Disabil Res.* 2019;63(12):1482–1487. 10.1111/jir.12672. [PubMed: 31313415]
2. Lauer E, Heslop P, Hoghton M. Identifying and addressing disparities in mortality: US and UK perspectives. *Int Rev Res Dev Disabil.* 2015;48:195–245. 10.1016/bs.irrdd.2015.03.002.
3. Centers for Disease Control and Prevention. Developmental disabilities. <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>. Published 2019. Accessed June 25, 2020.
4. Jha P Counting the dead is one of the world’s best investments to reduce premature mortality. *Hypothesis.* 2012;10(1):e1.
5. Landes SD, Stevens JD, Turk MA. 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.* 2019;9(2):e026614 10.1136/bmjopen-2018-026614.
6. Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open.* 2017;7(2):e013489 10.1136/bmjopen-2016-013489.
7. WHO. Disability. <http://www.who.int/topics/disabilities/en/>. Published 2018. Accessed January 8, 2020.
8. National Center for Health Statistics. Physicians’ handbook on medical certification of death. CDC [https://www.cdc.gov/nchs/data/misc/hb\\_cod.pdf](https://www.cdc.gov/nchs/data/misc/hb_cod.pdf). Published 2003. Accessed November 29, 2018.
9. Landes SD, Peek CW. Death by mental retardation? The influence of ambiguity on death certificate coding error for adults with intellectual disability. *J Intellect Disabil Res.* 2013;57(12):1183–1190. 10.1111/j.1365-2788.2012.01614.x. [PubMed: 22957894]
10. Office for National Statistics. Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/757010/guidance-for-doctors-completing-medical-certificates-of-cause-of-death.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/757010/guidance-for-doctors-completing-medical-certificates-of-cause-of-death.pdf). Published 2018. Accessed December 2019.
11. Turk MA, Fortuna RJ. Health status of adults with cerebral palsy In: Prasher VP, Janicki MP, eds. *Physical health of adults with intellectual and developmental disabilities.* 2nd ed. New York, NY: Springer; 2019:87–120. 10.1007/978-3-319-90083-4\_6.
12. Esbensen AJ, MacLean WE. Down syndrome In: Wehmeyer ML, ed. *A comprehensive guide to intellectual and developmental disabilities.* 2nd ed. Baltimore, MD: Brookes Publishing; 2017:195–208.
13. Santoro JD, Yedla M, Lazzareschi DV, Whitgob EE. Disability in US medical education: disparities, programmes and future directions. *Health Educ J.* 2017;76(6):753–759. 10.1177/0017896917712299.
14. Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *J Intellect Disabil Res.* 2009;53(11):898–904. 10.1111/j.1365-2788.2009.01201.x. [PubMed: 19694898]
15. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev.* 2006;12(1):70–82. 10.1002/mrdd.20098. [PubMed: 16435327]
16. Evenhuis HM, Henderson CM, Beange H, Lennox N, Chicoine B. *Healthy ageing - adults with intellectual disabilities: physical health issues.* Geneva, Switzerland: WHO; 2000.
17. Lutzker JR, Guastaferrro K, Benka-Coker ML. *Maltreatment of people with intellectual and developmental disabilities.* Silver Spring, MD: American Association of Intellectual and Developmental Disabilities; 2016.
18. Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? *J Appl Res Intellect Disabil.* 2013;27(5):431–446. 10.1111/jar.12067. [PubMed: 23913632]

**Table 1.**

## Types of Intellectual and Developmental Disabilities and Corresponding ICD-10 Codes

<b>Diagnosis description</b>	<b>ICD-10-CM diagnosis codes</b>
Intellectual disabilities	F70, F71, F72, F73, F78, F79
Pervasive developmental disorders – includes Autistic disorder, Rett’s syndrome, and Asperger’s syndrome	F84.0, F84.3, F84.5, F84.8, F84.9
Cerebral palsy	G80.0, G80.1, G80.2, G80.3, G80.4, G80.8, G80.9
Fetal alcohol syndrome	Q86.0
Down syndrome	Q90.0, Q90.1, Q90.2, Q90.9
Chromosomal abnormalities – includes Trisomies and Monosomies	Q91.0, Q91.1, Q91.2, Q91.3, Q91.4, Q91.5, Q91.6, Q91.7, Q92.0, Q92.1, Q92.2, Q92.5, Q92.62, Q92.7, Q92.8, Q92.9, Q93.0, Q93.1, Q93.2, Q93.3, Q93.4, Q93.5, Q93.7, Q93.81, Q93.88, Q93.89, Q93.9
Fragile X syndrome	Q99.2

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**Table 2.**

Example of Inaccurate and Accurate Reporting Cerebral Palsy on the Death Certificate

Cause-of-death section	Inaccurate reporting	Inaccurate reporting	Accurate reporting
Part 1 (Cause of death)			
Line 1 (Immediate cause)	Cardiac arrest, cause unspecified (ICD-10 I46.9)	Cardiac arrest, cause unspecified (ICD-10 I46.9)	Cardiac arrest, cause unspecified (ICD-10 I46.9)
Line 2	Acute kidney failure (ICD-10 N17.9)	Acute kidney failure (ICD-10 N17.9)	Acute kidney failure (ICD-10 N17.9)
Line 3	Pneumonia, unspecified organism (ICD-10 J18.9)	<b>Pneumonia, unspecified organism (ICD-10 J18.9)</b>	<b>Pneumonia, unspecified organism (ICD-10 J18.9)</b>
Line 4	<b>Cerebral palsy (ICD-10 G80.9)</b>		
Part 2 (Other significant conditions contributing to death)			Cerebral palsy (ICD-10 G80.9)

*Note:* Bold lettering indicates reported underlying cause of death.

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