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Mortality among youth and young adults with autism, intellectual disability, or cerebral palsy

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Abstract

Importance: Autism spectrum disorder (ASD), intellectual disability (ID), and cerebral palsy (CP) are lifelong neurodevelopmental conditions accompanied by varying impairments. U.S. mortality data for these groups are limited.

Objective: To compare mortality and causes of death among a multisite cohort identified at age 8 years with ASD, ID, or CP to the general population through youth or young adulthood.

Design, Setting, and Participants: Nine U.S. sites identified 32,787 individuals who met case definitions for ASD, ID, and/or CP at age 8 years during active population-based cross-sectional surveillance conducted biennially from 2000–2016 through the US Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) Network. Individuals were linked to death certificates through 2021. Cases with multiple conditions (18.9%) were included in each case group. General population data from the National Vital Statistics

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ACCESS TO DATA AND DATA ANALYSIS

Dr. Shaw had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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System were matched to ADDM Network sites and years of participation. Analyses were completed in 2024.

Exposure(s): ASD, ID, or CP.

Main Outcomes and Measures: Death and International Classification of Diseases, 10th revision (ICD-10) causes from death certificate linkage.

Results: There were 145 deaths among 23,393 people with ASD, 285 deaths among 14,031 people with ID, and 123 deaths among 1,612 people with CP. Increased mortality compared to the general population was seen for ASD (hazard ratio [HR]: 1.35; 95% CI: 1.15-1.59), ID (HR: 4.35; 95% CI: 3.87-4.88), and CP (HR: 9.62; 95% CI: 8.06-11.48). Further stratified by sex and co-occurring ID, mortality for ASD was higher only for females with co-occurring ID (HR: 5.04; 95% CI: 3.21-7.91) compared to females in the general population. The distribution of causes of death varied across groups. The most common underlying cause of death ICD-10 chapter was External causes of morbidity and mortality (V01-Y98) for the general population and ASD case group and Diseases of the nervous system (G00-G99) for CP and ID case groups. The only ICD chapter hazard of death that was not elevated for ID and CP compared to the general population was external causes as underlying cause of death; mortality from external causes was also not elevated as underlying or any cause of death for ASD. There were also notable sub-chapter mortality differences with important clinical and public health implications. Only 11% of those with ASD, 1% of those with ID, and 49% of those with CP had an ICD-10 code for the respective disability on their death certificate.

Conclusions and Relevance: Individuals with ASD, ID, or CP experienced higher mortality from a range of causes compared to the general population in youth and young adulthood. Mortality among these groups is difficult to ascertain using death certificates alone, since ICD-10 codes for these disabilities were rarely listed. These findings can inform public health and healthcare strategies to understand and prevent health disparities and excess mortality associated with developmental disabilities.

INTRODUCTION

Autism spectrum disorder (ASD), intellectual disability (ID), and cerebral palsy (CP) are lifelong neurodevelopmental conditions accompanied by a range of impairments and co-occurring health conditions. ASD is characterized by social communication deficits and restricted or repetitive behaviors[1]. ID is an impairment of general mental ability that impacts adaptive functioning in conceptual, social, and practical domains[1]. CP is a non-progressive movement disorder causing activity limitation and attributed to damage to the developing fetal or infant brain[2]. In the United States (US), more than 3% of children are identified with ASD[3,4], 1-2% with ID[5,6], and 0.3% with CP[7,8]. These conditions often overlap, e.g., with co-occurring ID reported for 39.6% of children with ASD[3] and 52% of children with CP[9]. Studies have found increased mortality risk for children and adults with ASD[10-22], ID[23-34], and CP[35-37] compared to the general population in multiple countries. National data systems in Australia, the United Kingdom, Finland, Denmark, and Taiwan have facilitated large mortality studies among people with developmental disabilities. Similar national data systems are unavailable in the US, limiting population sample size and geographic coverage of extant mortality studies. Some studies have relied on cause of death from death

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certificates to define case status[38,39], though the extent to which this could undercount cases or bias results is unknown.

To better characterize mortality associated with ASD, ID, and CP in the US, this report uses data from the Autism and Developmental Disabilities Monitoring (ADDM) Network, an active, population-based surveillance system that has tracked prevalence of ASD and other developmental disabilities in US communities since 2000. These population-level data reflect the distribution of underlying risk factors and co-occurring conditions, changes in diagnostic practices over time (as with ASD), and availability of improved treatments (as with CP). This study linked data of 8-year-old children identified with ASD, ID, or CP to death certificates to compare mortality and causes of death across the three groups and to the general population.

METHODS

ADDM Network site staff accessed health and education records as authorized under 45 CFR Part 46 and 34 CFR Section 99.35 and met applicable local institutional review board, privacy, and confidentiality requirements. This report followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

ADDM Network cases and deaths

This study included 32,787 8-year-old children identified with ASD or ID by the ADDM Network from 2000–2016 at nine sites (Arizona, Arkansas, Georgia, Maryland, Missouri, New Jersey, Tennessee, Utah, Wisconsin) or CP from 2000–2010 at 3 sites (Georgia, Missouri, and Wisconsin) (eMethods). Surveillance areas were as described in surveillance reports[40-47] except Arkansas was not able to access data for 2002. Participating ADDM Network sites and surveillance areas varied over time (eTable 1) and education records were not available at all sites. Sex and race/ethnicity were collected from abstracted records or birth certificates. Race/ethnicity was included in this study to examine potential differences in survival and used ADDM Network reporting categories: Asian or Pacific Islander, Hispanic or Latino (Hispanic) of any race, non-Hispanic Black (Black), and non-Hispanic White (White). To determine case status, information about characteristics, behaviors, and symptoms related to developmental conditions were abstracted from health or education records. Clinicians reviewed the aggregated data and applied standardized surveillance case definitions (eMethods); full methods and case definitions for ADDM Network surveillance years are available for ASD and ID[6,40-47] and CP[7,48-51]. Identifiers were submitted to the National Center for Health Statistics (NCHS) National Death Index (NDI)[52] for linkage to death certificates from 2000 through 2021. Death certificate matches were included if they met NCHS-recommended probabilistic linkage score cutoffs[53] (match scores for 96% of remaining matches were also higher than the more stringent cutoff range from NCHS). Matches that conflicted with ADDM records (conflicting birth year n=3 or death prior to surveillance year n=21) were removed.

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NCHS National Vital Statistics System (NVSS) general population counts

Population denominators from NVSS[54] and deaths from NVSS Detailed Mortality restricted-use data files[55] for 2000-2021 were matched to participating ADDM Network sites and ages for each cohort from 2000-2021 (eTable 2 and eTable 3). Case group death and population counts were not removed from the general population data.

International Classification of Diseases, 10th revision (ICD-10) cause of death codes

ICD-10 codes for underlying and multiple cause of death were available for analysis. The underlying cause of death is the disease or injury that initiated the chain of morbid events that led directly and inevitably to death[56]. Multiple cause (referred to as "any cause" in this report) of death codes include the underlying cause and other conditions listed on the death certificate. ICD-10 codes for case group conditions (ASD: F84 range excluding F84.2 Rett disorder[3,57]; ID: F70-F79; CP: G80 range) were investigated. ICD-10 codes were also grouped into ICD-10 chapters for analysis (see eTable 4 for chapter groupings and abbreviations). For example, ICD-10 codes from V01 through Y98 comprise Chapter XX External Causes of Morbidity and Mortality[58] (referred to as "external causes" in this report). To analyze subchapter causes of death, selected a priori based on previous literature, NVSS ICD-10 cause recode values (113 or 358 groupings) or a specific ICD code (e.g., I46 cardiac arrest) were used[53].

Statistical analysis

Because individuals with ASD, CP, or ID often have co-occurring diagnoses, cases were included in each group for which they met the surveillance case definition. eFigure 1 shows co-occurrence of the different conditions among children submitted to NDI and linked to death certificates. These percentages represent co-occurrence within participating sites which may not have had data for CP or ID for all years (eTable 1). Of the 32,787 individuals submitted to NDI, most (81.1%) had one condition; 17.0% had ASD and ID; 1.4% had CP and ID; 0.2% had ASD and CP; and 0.2% had all three (eFigure 1). Pearson chi-square or Fisher exact tests were used to compare children with ASD, ID, or CP who died and those who did not die stratified by case group, sex, race/ethnicity, and co-occurring ID (for ASD and CP). Individuals with missing data (or other race/ethnicity) were excluded from analyses stratified by that variable (sex missing for <0.1% ID; race/ethnicity missing for 5.6% ASD, 5.7% CP, and 4.1% ID; co-occurring ID information missing for 25.8% ASD and 46.9% CP). Pearson chi-square or Fisher exact tests were considered significant when $p<0.05$. For survival analysis, start time was age at ascertainment minus one for case groups, since children were alive through age 7 years but could have died at age 8 years. Event time was age at death for those who died; censoring time was age in 2021 for those who did not die. Because general population data were single-year-of-age cross-sectional estimates, start time was age at observation year minus one, and the event time (for those who died) or censoring time (for those who did not die) was age at observation year. Cumulative survival from age 8 to age 29 years was visualized in Kaplan-Meier survival curves and hazard ratios (HRs) were calculated overall, by sex, or by cause of death using Cox proportional hazards models by case group (3-level: ASD, ID, and CP or 5-level: ASD+ID, ASD-ID, ID, CP+ID, CP-ID) (eTable 5). For causes of death, hazards were calculated for case groups with 5 or

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more deaths from that cause. HRs were considered significant when the unrounded 95% confidence interval (CI) did not include 1. Models with significant effects that violated the proportional hazards assumption were run stratified by roughly equal age intervals (8-12, 13-17, 18-22, and 23-29 years), and none demonstrated a significant effect that was opposite of the overall finding. Overall ratios from these models should be interpreted as a weighted average of the HRs over the entire follow-up period[59].

RESULTS

There were 23 393 people with ASD (among those with available data, sex: 81.7% male; race and ethnicity: 59.5% White, 21.6% Black, 15.0% Hispanic, and 4.0% Asian or Pacific Islander), 14 031 people with ID (among those with available data, sex: 67.8% male; race and ethnicity: 37.6% White, 36.9% Black, 21.7% Hispanic, and 3.8% Asian or Pacific Islander), and 1612 people with CP (among those with available data, sex: 57.6% male; race and ethnicity: 47.1% White, 41.0% Black, 8.8% Hispanic, and 3.2% Asian or Pacific Islander) (eTable 6). There were 145 deaths in the ASD group, 285 deaths in the ID group, and 123 deaths in the CP group during youth and young adulthood from 2000 through 2021. Among those who died, 16 with ASD (11.0%) had ASD listed as any cause of death, 3 with ID (1.1%) had ID listed as any cause of death, and 60 with CP (48.8%) had CP listed as any cause of death (eFigure 2).

Characteristics of individuals in case groups who died and those who did not die

Complete demographic data for case groups overall and stratified by those who died and did not die between age 8 and 29 years is available in eTable 6. Individuals who died and those who did not die had similar distribution of sex for ASD (82.1% and 81.7% male; p=0.99) and CP (58.5% and 57.5% male; p=0.90), but there was a lower percentage of males among those with ID who died compared to those who did not die (59.3% and 68.0% male, p=0.002) (Figure 1). For ASD, individuals who died and those who did not die were not significantly different by race and ethnicity (majority White followed by Black and Hispanic). Race and ethnicity was significantly different between individuals who died and those who did not die for CP (majority Black [52.9%] compared with highest percentage White [47.9%]) and ID (though in this group order of race by frequency remained the same). Co-occurring ID was more common among individuals who died than those who did not die for ASD (62.1% compared to 33.8%; p<0.001) and CP (96.9% compared to 59.2%; p<0.001).

Cumulative survival

Cumulative survival from age 8 to age 29 years was 98.4% (95% CI: 98.3%-98.4%) for the general population, 97.7% (95% CI: 97.1%-98.3%) for ASD (HR: 1.35, 95% CI: 1.15-1.59), 94.7% (95% CI: 93.6%-95.8%) for ID (HR: 4.35, 95% CI: 3.87-4.88), and 90.5% (95% CI: 88.8%-92.3%) for CP (HR: 9.62, 95% CI: 8.06-11.48) (Figure 2, eTable 5). Mortality was higher for males than females in the general population (HR: 2.34; 95% CI: 2.29-2.40), was similar for males and females with ASD and CP, and was lower for males than females with ID (HR: 0.72; 95% CI: 0.57-0.91) (eFigure 3).

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For individuals with ASD, sex-specific mortality was similar to the general population for males with and without co-occurring ID and females without co-occurring ID (eTable 5). Females with ASD and co-occurring ID had higher mortality than the general female population (HR: 5.04; 95% CI: 3.21-7.91). For individuals with CP, mortality was higher for males with (HR: 10.00; 95% CI: 7.18-13.93) and without co-occurring ID (HR: 5.37; 95% CI: 3.89-7.41) and females with (HR: 24.43; 95% CI: 16.86-35.40) and without co-occurring ID (HR: 11.63; 95% CI: 7.72-17.51) compared to sex-specific mortality in the general population.

Underlying causes of death

Causes of death were more varied among case groups than the general population, where 71.9% of underlying causes of death were from the top chapter cause of death (Figure 3). The external causes chapter was the most common underlying cause of death in the general population and ASD group, the second most common for those with ID, and the third most common for those with CP (Figure 3, eTable 7). The second most common underlying cause of death in the general population was neoplasms, which was not in the top 5 chapters for any case group. Nervous system diseases (which include CP ICD-10 codes) were the most common cause of death for those with ID and CP, second most common for those with ASD, and fourth most common for the general population.

ICD-10 chapter cause-specific mortality

For ICD-10 code chapters with ≥5 deaths in the ASD group, individuals with ASD experienced higher mortality from 8 of 11 chapters as underlying cause (HRs from 2.59 to 9.04) and 11 of 13 ICD-10 code chapters as any cause of death (HRs from 2.27 to 4.42) compared to the general population (Table 1). Mortality was similar for neoplasms and external causes as underlying or any cause of death and for circulatory system as an underlying cause.

Compared to the general population for ICD-10 code chapters with ≥5 deaths in the ID or CP case groups, respectively, individuals with ID experienced higher mortality from 11 of 12 ICD-10 code chapters as underlying cause (HRs from 3.27 to 30.84) and 16 of 16 ICD-10 code chapters as any cause of death (HRs from 1.33 to 31.27); individuals with CP experienced higher mortality from 7 of 8 ICD-10 code chapters as underlying cause (HRs from 14.62 to 114.57) and 12 of 12 ICD-10 code chapters as any cause of death (HRs from 2.50 to 285.79). The only hazard of death that was not elevated for ID and CP compared to the general population was external causes as underlying cause of death.

Unintentional and intentional external causes and other cause-specific mortality for case groups with at least five deaths from the subchapter cause

Compared to the general population, mortality from transport accidents did not significantly differ for individuals with ID; individuals with ASD had half the hazard of death (HR: 0.45, 95% CI: 0.24-0.84) (Table 2). Compared to the general population, the group with ASD had similar mortality from non-transport accidents while there was increased mortality for those with ID (HR: 2.68, 95% CI: 1.88-3.82) and CP (HR: 5.35, 95% CI: 3.10-9.22). Within non-transport accidents, those with ASD and ID had elevated mortality from death from

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accidental drowning and submersion (ASD HR: 3.34, 95% CI: 1.58-7.03; ID HR: 5.49, 95% CI: 2.60-11.57) compared to the general population. Of seven ASD drowning deaths, four occurred in a swimming pool and three in a bathtub. Of seven ID drowning deaths, four occurred in a swimming pool, one in a bathtub, and two in natural water. Mortality from other accidental threats to breathing (due to inhalation and ingestion of objects) was higher for individuals with ID (HR: 26.32, 95% CI: 15.63-44.33) and CP (HR: 88.01, 95% CI: 43.53-177.94) compared to the general population. Within this group, 14 of 15 ID deaths and all eight CP deaths were from "other" or unspecified objects, with food specified as the cause of one ID death. For individuals with ASD, mortality from accidental poisoning and exposure to noxious substances as well as intentional self-harm (suicide) did not differ from the general population. Mortality from assault (homicide) was lower for the group with ASD (HR: 0.45; 95% CI: 0.22-0.95) and did not differ for ID compared to the general population.

The hazard of death from drug use disorders was similar for individuals with ASD compared to the general population. Mortality from epilepsy was elevated compared to the general population for ASD (HR: 8.85; 95% CI: 4.86-16.14), ID (HR: 22.51; 95% CI 13.83-36.63), and CP (HR 60.21; 95% CI: 29.87-121.35). Mortality from cardiac arrest was also elevated compared to the general population for ASD (HR: 2.77, 95% CI: 1.63-4.68), ID (HR: 17.27; 95% CI 13.13-22.71), and CP (HR: 42.18; 95% CI: 27.94-63.67). Compared to the general population, mortality from COVID-19 was 4.61 (95% CI: 1.91-11.14) times as high for ASD and 7.71 (95% CI: 3.19-18.64) times as high for ID (Table 2).

DISCUSSION

Mortality for case groups was higher than the general population for most causes, reflecting higher medical needs and the need for strategies to reduce disparities in deaths among youth and young adults with disabilities. Though co-occurring ID was likely under-ascertained since IQ data were not available for all sites, the combination of multiple disabilities was still strongly associated with mortality. Mortality for ASD without ID was similar to the general population, consistent with other studies adjusting for co-occurring conditions[12,21,22]. Studies of recent ASD cohorts have found mortality similar to the general population[11,15,20,60], while higher mortality has been reported for ASD cohorts ascertained in earlier years[18,19] when a higher proportion of cases had profound ASD or ASD with co-occurring ID[61,62]. While ASD alone might not increase mortality, studies collectively point to importance of clinical assessment and management of high-risk co-occurring conditions[12,21,22].

Females with ID had higher mortality than males with ID and higher mortality was seen among females but not males with ASD and co-occurring ID compared to the general population. Many studies have found higher mortality for females with ID[23,25-28,32-34] or ASD and ID[18,20] compared to males with the same conditions and within further stratification of ID by IQ level[23-26,28]. One study among international experts reported consensus of this gender-based mortality difference existing, but cause-specific and characteristic-specific explanations lacking sufficient evidence[63].

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Individuals with CP who died were disproportionately Black. One study found CP and severe functional limitations were more common among Black children[64], which could reflect higher risk of being born premature, at low birth weight, and small for gestational age[65]. These birth outcomes are linked to social determinants of health[66-68], potential targets for public health intervention. Larger linkage studies could examine any disability-specific differences in mortality by race/ethnicity compared to general population patterns[69]. Similarly, longer follow-up studies could assess any disability-specific increases in mortality with age[70].

Individuals with CP or ID experienced much higher mortality from accidental threats to breathing. Indications of choking could differ in these populations depending on motor or other functional limitations. It is important for caregivers to recognize signs of choking and how to effectively intervene with the Heimlich maneuver[71,72]. In addition to mortality from choking, the highly prevalent difficulty swallowing can lead to recurrent chest infections or pneumonia leading to respiratory-associated death[73-75].

Other studies have found increased suicide risk in individuals with ASD diagnosed at any age[11,14,76], while our study included only individuals identified by age 8 years and followed until a maximum of age 29 years. Though ASD suicide mortality was similar to the general population in our study, suicide is still a leading cause of death for youth and young adults in recent years[77]. Co-occurring psychiatric conditions affect suicide risk in people with ASD[21], reinforcing the importance of identifying and managing co-occurring conditions.

Similar mortality from drug use disorders for ASD relative to the population in our study could reflect younger ages and higher presence of co-occurring ID compared to studies that found higher substance use or death among individuals with ASD[78-80]. Lower mortality from homicide is difficult to interpret given the lack of comparable estimates in literature. Higher mortality from COVID-19 for ASD and ID was consistent with other studies[81-83].

Reduced transport accident mortality for ASD could relate to ages included in this study and overall lower likelihood of having a driver's license[84,85]. Lower transport accident mortality has previously been reported among young people with ID[86]. The US Department of Transportation reported individuals with disabilities were less likely to travel, be employed, or live in a household with a vehicle[87]. Lower mortality could therefore indicate lack of transportation, which is a barrier to community participation[88].

According to death certificate reporting guidance, a developmental disability can be listed as a cause of death if it was present at the time of death and contributed to the death[89]. Only 1% of ID deaths, 11% of ASD deaths, and 49% of CP deaths included ICD-10 codes for the respective disability, consistent with other studies that found most individuals with ASD, CP, or ID did not have the disability on their death certificate[90,91]. This is important when evaluating findings from studies that ascertain disability only from death certificates. For example, an often-cited 160 times higher risk of drowning for children with ASD[92] relied on ASD ICD codes listed as cause of death[38]. ASD could be more likely to appear for a drowning death given, e.g., awareness of wandering behaviors[93], biasing results. Though not a top cause of death in our study, higher mortality from drowning is still a target for public

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health intervention. Almost half of ASD drowning deaths occurred in bathtubs, an important consideration for drowning prevention campaigns.

Linkages between death certificates and systems with information about developmental disabilities, such as our study using active surveillance data collected systematically in 9 US states, offer more complete identification of developmental disabilities than death certificates alone and allow comparisons to the general population. This study can inform efforts to reduce mortality among people with ASD, ID, or CP.

STRENGTHS AND LIMITATIONS

To our knowledge, this is the largest US multisite and multi-disability study of mortality among youth and young adults with ASD, CP, or ID. These data represent population-based cohorts from 9 US sites but are not nationally representative. Data quality was dependent on the availability and completeness of records. ID and CP surveillance were not performed at all sites during all years, so estimates of co-occurrence are likely under-estimates. Rather than rely on death certificate disability ICD codes, our study used active surveillance methods to review information from both health and education sources for comprehensive case determination to generate population-based estimates.

CONCLUSIONS

In this study, youth and young adults with ID and CP experienced higher mortality compared to the general population. For ASD, females with co-occurring ID experienced higher mortality, but mortality for males with co-occurring ID and males and females without co-occurring ID was similar to the general population. Deaths causes were diverse and reflect medical complexity of developmental conditions, including co-occurrence of multiple disabilities. Relying on disabilities listed on death certificates would not identify most cases and could bias mortality estimates. Public health and healthcare strategies could help prevent disparities in mortality associated with developmental disabilities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DISCLAIMER

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

CONFLICT OF INTEREST DISCLOSURES

Dr Bilder reported grants from US Centers for Disease Control and Prevention during the conduct of the study; personal fees from BioMarin Pharmaceuticals as a consultant, related to phenylketonuria and personal fees from Taysha Gene Therapies as a consultant, related to Rett Syndrome outside the submitted work. Dr Durkin reported grants from US Centers for Disease Control and Prevention during the conduct of the study. Dr Fitzgerald reported

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DATA SHARING STATEMENT

Case group data were collected as a public health surveillance activity and adhere to confidentiality and data sharing requirements of federal, state, and local public health authorities. Detailed general population death data are available with project approval from CDC's National Center for Health Statistics, or are available in aggregate from CDC WONDER along with corresponding general population counts.

REFERENCES

1. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision. American Psychiatric Association; 2022.
2. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007;109:8–14. [PubMed: 17370477]
3. Shaw KA, Williams S, Patrick ME, et al. Prevalence and Early Identification of Autism Spectrum Disorder Among Children Aged 4 and 8 Years - Autism and Developmental Disabilities Monitoring Network, 16 Sites, United States, 2022. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2025;74(2):1–22. doi:10.15585/mmwr.ss7402a1
4. 2022-2023 National Survey of Children's Health Child and Family Health Measures. Accessed April 11, 2025. https://www.childhealthdata.org/browse/survey/results?q=11080&r=1
5. Zablotsky B, Ng AE, Black LI, Blumberg SJ. Diagnosed Developmental Disabilities in Children Aged 3-17 Years: United States, 2019-2021. NCHS Data Brief. 2023;(473):1–8.
6. Patrick ME, Shaw KA, Dietz PM, et al. Prevalence of intellectual disability among eight-year-old children from selected communities in the United States, 2014. Disabil Health J. 2021;14(2):101023. doi:10.1016/j.dhjo.2020.101023 [PubMed: 33272883]
7. Durkin MS, Benedict RE, Christensen D, et al. Prevalence of Cerebral Palsy among 8-Year-Old Children in 2010 and Preliminary Evidence of Trends in Its Relationship to Low Birthweight. Paediatr Perinat Epidemiol. 2016;30(5):496–510. doi:10.1111/ppe.12299 [PubMed: 27215680]
8. Zablotsky B, Black LI. Prevalence of Children Aged 3-17 Years With Developmental Disabilities, by Urbanicity: United States, 2015-2018. Natl Health Stat Rep. 2020;(139):1–7.
9. Van Naarden Braun K, Christensen D, Doernberg N, et al. Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan atlanta, 1991-2010. PloS One. 2015;10(4):e0124120. doi:10.1371/journal.pone.0124120 [PubMed: 25923140]
10. Pickett JA, Paculdo DR, Shavelle RM, Strauss DJ. 1998-2002 Update on "Causes of death in autism". J Autism Dev Disord. 2006;36(2):287–288. doi:10.1007/s10803-005-0066-x [PubMed: 16565885]
11. Schendel DE, Overgaard M, Christensen J, et al. Association of Psychiatric and Neurologic Comorbidity With Mortality Among Persons With Autism Spectrum Disorder in a Danish Population. JAMA Pediatr. 2016;170(3):243–250. doi:10.1001/jamapediatrics.2015.3935 [PubMed: 26752506]
12. Bilder D, Botts EL, Smith KR, et al. Excess mortality and causes of death in autism spectrum disorders: a follow up of the 1980s Utah/UCLA autism epidemiologic study. J Autism Dev Disord. 2013;43(5):1196–1204. doi:10.1007/s10803-012-1664-z [PubMed: 23008058]

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13. Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T. Mortality and causes of death in autism spectrum disorders: an update. Autism Int J Res Pract. 2008;12(4):403–414. doi:10.1177/1362361308091653

14. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. Br J Psychiatry J Ment Sci. 2016;208(3):232–238. doi:10.1192/bjp.bp.114.160192

15. Hwang YIJ, Srasuebkul P, Foley KR, Arnold S, Trollor JN. Mortality and cause of death of Australians on the autism spectrum. Autism Res Off J Int Soc Autism Res. 2019;12(5):806–815. doi:10.1002/aur.2086

16. Catalá-López F, Hutton B, Page MJ, et al. Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis. JAMA Pediatr. 2022;176(4):e216401. doi:10.1001/jamapediatrics.2021.6401 [PubMed: 35157020]

17. Vu H, Bowden N, Gibb S, et al. Mortality risk among Autistic children and young people: A nationwide birth cohort study. Autism Int J Res Pract. Published online February 4, 2024:13623613231224015. doi:10.1177/13623613231224015

18. O'Nions E, Lewer D, Petersen I, et al. Estimating life expectancy and years of life lost for autistic people in the UK: a matched cohort study. Lancet Reg Health Eur. 2024;36:100776. doi:10.1016/j.lanepe.2023.100776 [PubMed: 38188276]

19. Tsai SJ, Chang WH, Cheng CM, et al. All-cause mortality and suicide mortality in autistic individuals: An entire population longitudinal study in Taiwan. Autism Int J Res Pract. 2023;27(8):2496–2506. doi:10.1177/13623613231167287

20. Huang YH, Wu SI, Lee MJ, et al. Excess Mortality in Individuals with Autism Spectrum Disorder: A Population-Based Cohort Study. Neuropsychiatr Dis Treat. 2024;20:247–255. doi:10.2147/NDT.S437766 [PubMed: 38348059]

21. Jokiranta-Olkoniemi E, Gyllenberg D, Sucksdorff D, et al. Risk for Premature Mortality and Intentional Self-harm in Autism Spectrum Disorders. J Autism Dev Disord. 2021;51(9):3098–3108. doi:10.1007/s10803-020-04768-x [PubMed: 33140146]

22. Gillberg C, Billstedt E, Sundh V, Gillberg IC. Mortality in autism: a prospective longitudinal community-based study. J Autism Dev Disord. 2010;40(3):352–357. doi:10.1007/s10803-009-0883-4 [PubMed: 19838782]

23. Hirvikoski T, Boman M, Tideman M, Lichtenstein P, Butwicka A. Association of Intellectual Disability With All-Cause and Cause-Specific Mortality in Sweden. JAMA Netw Open. 2021;4(6):e2113014. doi:10.1001/jamanetworkopen.2021.13014 [PubMed: 34156453]

24. Hosking FJ, Carey IM, Shah SM, et al. Mortality Among Adults With Intellectual Disability in England: Comparisons With the General Population. Am J Public Health. 2016;106(8):1483–1490. doi:10.2105/AJPH.2016.303240 [PubMed: 27310347]

25. Tyrer F, Smith LK, McGrother CW. Mortality in adults with moderate to profound intellectual disability: a population-based study. J Intellect Disabil Res JIDR. 2007;51(Pt 7):520–527. doi:10.1111/j.1365-2788.2006.00918.x [PubMed: 17537165]

26. Maenner MJ, Greenberg JS, Mailick MR. Association between mild intellectual disability and early mortality in men and women: evidence from a population-based cohort study. Am J Intellect Dev Disabil. 2015;120(3):244–257. doi:10.1352/1944-7558-120.3.244 [PubMed: 25928436]

27. Glover G, Williams R, Heslop P, Oyinlola J, Grey J. Mortality in people with intellectual disabilities in England. J Intellect Disabil Res JIDR. 2017;61(1):62–74. doi:10.1111/jir.12314 [PubMed: 27489075]

28. Arvio M, Salokivi T, Tiitinen A, Haataja L. Mortality in individuals with intellectual disabilities in Finland. Brain Behav. 2016;6(2):e00431. doi:10.1002/brb3.431 [PubMed: 26811802]

29. McCarron M, Carroll R, Kelly C, McCallion P. Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012. J Appl Res Intellect Disabil JARID. 2015;28(5):406–413. doi:10.1111/jar.12194 [PubMed: 26256275]

30. Reppermund S, Srasuebkul P, Dean K, Trollor JN. Factors associated with death in people with intellectual disability. J Appl Res Intellect Disabil JARID. 2020;33(3):420–429. doi:10.1111/jar.12684 [PubMed: 31786826]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

31. Doyle A, O'Sullivan M, Craig S, McConkey R. People with intellectual disability in Ireland are still dying young. J Appl Res Intellect Disabil JARID. 2021;34(4):1057–1065. doi:10.1111/jar.12853 [PubMed: 33377272]
32. Smith GS, Fleming M, Kinnear D, et al. Rates and causes of mortality among children and young people with and without intellectual disabilities in Scotland: a record linkage cohort study of 796 190 school children. BMJ Open. 2020;10(8):e034077. doi:10.1136/bmjopen-2019-034077
33. Hughes-McCormack LA, Rydzewska E, Cooper SA, et al. Rates, causes and predictors of all-cause and avoidable mortality in 163 686 children and young people with and without intellectual disabilities: a record linkage national cohort study. BMJ Open. 2022;12(9):e061636. doi:10.1136/bmjopen-2022-061636
34. Rydzewska E, Nijhof D, Hughes L, et al. Rates, causes and predictors of all-cause and avoidable mortality in 514 878 adults with and without intellectual disabilities in Scotland: a record linkage national cohort study. BMJ Open. 2025;15(2):e089962. doi:10.1136/bmjopen-2024-089962
35. Strauss D, Shavelle R, Reynolds R, Rosenbloom L, Day S. Survival in cerebral palsy in the last 20 years: signs of improvement? Dev Med Child Neurol. 2007;49(2):86–92. doi:10.1111/j.1469-8749.2007.00086.x [PubMed: 17253993]
36. Blair E, Langdon K, McIntyre S, Lawrence D, Watson L. Survival and mortality in cerebral palsy: observations to the sixth decade from a data linkage study of a total population register and National Death Index. BMC Neurol. 2019;19(1):111. doi:10.1186/s12883-019-1343-1 [PubMed: 31164086]
37. Ryan JM, Peterson MD, Ryan N, et al. Mortality due to cardiovascular disease, respiratory disease, and cancer in adults with cerebral palsy. Dev Med Child Neurol. 2019;61(8):924–928. doi:10.1111/dmcn.14176 [PubMed: 30727025]
38. Guan J, Li G. Injury Mortality in Individuals With Autism. Am J Public Health. 2017;107(5):791–793. doi:10.2105/AJPH.2017.303696 [PubMed: 28323463]
39. Peterson MD, Wilson AM, Hurvitz EA. Underlying Causes of Death among Adults with Cerebral Palsy. J Clin Med. 2022;11(21):6333. doi:10.3390/jcm11216333 [PubMed: 36362560]
40. Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2020;69(4):1–12. doi:10.15585/mmwr.ss6904a1
41. Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2018;67(6):1–23. doi:10.15585/mmwr.ss6706a1
42. Christensen DL, Baio J, Van Naarden Braun K, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years--Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2016;65(3):1–23. doi:10.15585/mmwr.ss6503a1
43. Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2014;63(2):1–21.
44. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2012;61(3):1–19.
45. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators, Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders - Autism and Developmental Disabilities Monitoring Network, United States, 2006. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2009;58(10):1–20.
46. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2007;56(1):12–28.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

47. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2000 Principal Investigators, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000. Morb Mortal Wkly Rep Surveill Summ Wash DC 2002. 2007;56(1):1–11.
48. Yeargin-Allsopp M, Van Naarden Braun K, Doernberg NS, Benedict RE, Kirby RS, Durkin MS. Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: a multisite collaboration. Pediatrics. 2008;121(3):547–554. doi:10.1542/peds.2007-1270 [PubMed: 18310204]
49. Arneson CL, Durkin MS, Benedict RE, et al. Prevalence of cerebral palsy: Autism and Developmental Disabilities Monitoring Network, three sites, United States, 2004. Disabil Health J. 2009;2(1):45–48. doi:10.1016/j.dhjo.2008.08.001 [PubMed: 21122742]
50. Kirby RS, Wingate MS, Van Naarden Braun K, et al. Prevalence and functioning of children with cerebral palsy in four areas of the United States in 2006: a report from the Autism and Developmental Disabilities Monitoring Network. Res Dev Disabil. 2011;32(2):462–469. doi:10.1016/j.ridd.2010.12.042 [PubMed: 21273041]
51. Christensen D, Van Naarden Braun K, Doernberg NS, et al. Prevalence of cerebral palsy, co-occurring autism spectrum disorders, and motor functioning - Autism and Developmental Disabilities Monitoring Network, USA, 2008. Dev Med Child Neurol. 2014;56(1):59–65. doi:10.1111/dmcn.12268 [PubMed: 24117446]
52. US Centers for Disease Control and Prevention. National Death Index. Accessed January 12, 2026. https://www.cdc.gov/nchs/ndi/
53. National Death Index User's Guide. Published online 2024. Accessed July 4, 2024. https://www.cdc.gov/nchs/data/ndi/2024-NDI-User-Guide.pdf
54. US Centers for Disease Control and Prevention. National Vital Statistics System. Accessed January 12, 2026. https://wonder.cdc.gov/wonder/help/ucd.html#Population%20Data%20Sources
55. US Centers for Disease Control and Prevention. Restricted-use vital statistics data. Accessed January 12, 2026. https://www.cdc.gov/nchs/nvss/nvss-restricted-data.htm
56. National Center for Health Statistics. Instructions for Completing the Cause-of-Death Section of the Death Certificate. Published online August 2004. https://www.cdc.gov/nchs/data/dvs/blue_form.pdf
57. National Center for Health Statistics. FY22 ICD-10-CM release. Accessed July 2, 2025. https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD10CM/2022/icd10cm_codes_2022.txt
58. ICD-10 Version:2019. Accessed November 13, 2024. https://icd.who.int/browse10/2019/en
59. Stensrud MJ, Hernán MA. Why Test for Proportional Hazards? JAMA. 2020;323(14):1401–1402. doi:10.1001/jama.2020.1267 [PubMed: 32167523]
60. Smith GS, Fleming M, Kinnear D, et al. Mortality in 787,666 school pupils with and without autism: A cohort study. Autism Int J Res Pract. 2021;25(1):300–304. doi:10.1177/1362361320944037
61. Shaw KA, McArthur D, Hughes MM, et al. Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016. J Am Acad Child Adolesc Psychiatry. Published online November 22, 2021:S0890-8567(21)02000-1. doi:10.1016/j.jaac.2021.11.019
62. Hughes MM, Shaw KA, DiRienzo M, et al. The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000-2016. Public Health Rep Wash DC 1974. 2023;138(6):971–980. doi:10.1177/00333549231163551
63. Robertson J, Heslop P, Lauer E, Taggart L, Hatton C. Gender and the Premature Deaths of People with Intellectual Disabilities: An International Expert Consultation. J Policy Pract Intellect Disabil. 2021;18(2):89–103. doi:10.1111/jppi.12360
64. Maenner MJ, Benedict RE, Arneson CL, et al. Children with cerebral palsy: racial disparities in functional limitations. Epidemiol Camb Mass. 2012;23(1):35–43. doi:10.1097/EDE.0b013e31823a4205
65. Barfield WD. Public Health Implications of Very Preterm Birth. Clin Perinatol. 2018;45(3):565–577. doi:10.1016/j.clp.2018.05.007 [PubMed: 30144856]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

66. Durkin MS, Yeargin-Allsopp M. Socioeconomic Status and Pediatric Neurologic Disorders: Current Evidence. Semin Pediatr Neurol. 2018;27:16–25. doi:10.1016/j.spen.2018.03.003 [PubMed: 30293586]

67. Behrman RE, Butler AS, Outcomes I of M (US) C on UPB and AH. Sociodemographic and Community Factors Contributing to Preterm Birth. In: Preterm Birth: Causes, Consequences, and Prevention. National Academies Press (US); 2007. Accessed October 6, 2024. https://www.ncbi.nlm.nih.gov/books/NBK11388/

68. Lorch SA, Enlow E. The role of social determinants in explaining racial/ethnic disparities in perinatal outcomes. Pediatr Res. 2016;79(1-2):141–147. doi:10.1038/pr.2015.199 [PubMed: 26466077]

69. Wolf ER, Rivara FP, Orr CJ, Sen A, Chapman DA, Woolf SH. Racial and Ethnic Disparities in All-Cause and Cause-Specific Mortality Among US Youth. JAMA. 2024;331(20):1732–1740. doi:10.1001/jama.2024.3908 [PubMed: 38703403]

70. Bernal J, Wiese MY, Todd S. How People with Intellectual Disability Are Dying and Implications for Quality Care. In: Stancliffe RJ, Wiese MY, McCallion P, McCarron M, eds. End of Life and People with Intellectual and Developmental Disability: Contemporary Issues, Challenges, Experiences and Practice. Springer International Publishing; 2022:149–177. doi:10.1007/978-3-030-98697-1_6

71. Adult & Child Choking: Symptoms and First Aid. Red Cross. Accessed January 27, 2025. https://www.redcross.org/take-a-class/resources/learn-first-aid/adult-child-choking

72. Cash S, Shinnick-Page A. Basic life support and children with profound and multiple learning disabilities. Paediatr Nurs. 2008;20(8):38–39. doi:10.7748/paed2008.10.20.8.38.c8267

73. Truesdale M, Melville C, Barlow F, et al. Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis. BMJ Open. 2021;11(7):e043658. doi:10.1136/bmjopen-2020-043658

74. Perez CM, Ball SL, Wagner AP, Clare ICH, Holland AJ, Redley M. The incidence of healthcare use, ill health and mortality in adults with intellectual disabilities and mealtime support needs. J Intellect Disabil Res JIDR. 2015;59(7):638–652. doi:10.1111/jir.12167 [PubMed: 25363017]

75. Calderone A, Militi D, Cardile D, Corallo F, Calabrò RS, Militi A. Swallowing disorders in cerebral palsy: a systematic review of oropharyngeal Dysphagia, nutritional impact, and health risks. Ital J Pediatr. 2025;51(1):57. doi:10.1186/s13052-025-01903-1 [PubMed: 39985076]

76. Kirby AV, Bakian AV, Zhang Y, Bilder DA, Keeshin BR, Coon H. A 20-year study of suicide death in a statewide autism population. Autism Res Off J Int Soc Autism Res. 2019;12(4):658–666. doi:10.1002/aur.2076

77. Curtin SC MA, Garnett MF MPH Products - Data Briefs - Number 471 - June 2023. doi:10.15620/cdc:128423

78. Butwicka A, Långström N, Larsson H, et al. Increased Risk for Substance Use-Related Problems in Autism Spectrum Disorders: A Population-Based Cohort Study. J Autism Dev Disord. 2017;47(1):80–89. doi:10.1007/s10803-016-2914-2 [PubMed: 27734228]

79. Haasbroek H, Morojele N. A Systematic Literature Review on the Relationship Between Autism Spectrum Disorder and Substance Use Among Adults and Adolescents. Rev J Autism Dev Disord. 2022;9(1):1–20. doi:10.1007/s40489-021-00242-1

80. Ressel M, Thompson B, Poulin MH, et al. Systematic review of risk and protective factors associated with substance use and abuse in individuals with autism spectrum disorders. Autism Int J Res Pract. 2020;24(4):899–918. doi:10.1177/1362361320910963

81. Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disabil Health J. 2020;13(3):100942. doi:10.1016/j.dhjo.2020.100942 [PubMed: 32473875]

82. Davis A, Van Eck K, Copeland-Linder N, Phuong K, Belcher HME. Hospitalization and Mortality for Insured Patients in the United States with COVID-19 with and without Autism Spectrum Disorder. J Autism Dev Disord. 2024;54(6):2347–2354. doi:10.1007/s10803-023-05971-2 [PubMed: 37022580]

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83. Kuper H, Smythe T. Are people with disabilities at higher risk of COVID-19-related mortality?: a systematic review and meta-analysis. Public Health. 2023;222:115–124. doi:10.1016/j.puhe.2023.06.032 [PubMed: 37541064]
84. Curry AE, Yerys BE, Huang P, Metzger KB. Longitudinal study of driver licensing rates among adolescents and young adults with autism spectrum disorder. Autism Int J Res Pract. 2018;22(4):479–488. doi:10.1177/1362361317699586
85. Kirby AV, Bilder DA, Nicholls C, McMahon WM, Bakian AV. Using State Administrative Data to Examine Aspects of Autistic Adult Life: A Comparative Analysis of Identification, Voting, Marriage, and Parenting. Autism Adulthood. Published online November 27, 2024. doi:10.1089/aut.2024.0183
86. Sherrard J, Tonge BJ, Ozanne-Smith J. Injury in young people with intellectual disability: descriptive epidemiology. Inj Prev J Int Soc Child Adolesc Inj Prev. 2001;7(1):56–61. doi:10.1136/ip.7.1.56
87. Travel Patterns of American Adults with Disabilities | Bureau of Transportation Statistics. Accessed October 6, 2025. https://www.bts.gov/travel-patterns-with-disabilities
88. Verdonschot MML, de Witte LP, Reichrath E, Buntinx WHE, Curfs LMG. Impact of environmental factors on community participation of persons with an intellectual disability: a systematic review. J Intellect Disabil Res JIDR. 2009;53(1):54–64. doi:10.1111/j.1365-2788.2008.01128.x [PubMed: 19093982]
89. National Center for Health Statistics National Vital Statistics System. Physician's Handbook on Medical Certification of Death. https://www.cdc.gov/nchs/data/nvss/handbook/2023-physicians-mcod-handbook.pdf
90. Dunwoodie Stirton F, Heslop P. Medical Certificates of Cause of Death for people with intellectual disabilities: A systematic literature review. J Appl Res Intellect Disabil JARID. 2018;31(5):659–668. doi:10.1111/jar.12448 [PubMed: 29573517]
91. Glover G, Ayub M. How People With Learning Disabilities Die. Published online 2010. https://www.researchgate.net/publication/257984926_How_People_With_Learning_Disabilities_Die
92. Individuals with Autism at Substantially Heightened Risk for Injury Death. Columbia University Mailman School of Public Health. March 21, 2017. Accessed July 4, 2024. https://www.publichealth.columbia.edu/news/individuals-autism-substantially-heightened-risk-injury-death
93. Hyman SL, Levy SE, Myers SM, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. Published online December 16, 2019. doi:10.1542/peds.2019-3447

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Key Points

Question:

How do mortality and causes of death for individuals with autism spectrum disorder (ASD), intellectual disability (ID), or cerebral palsy (CP) compare to the general population?

Findings:

This population-based cohort study found significantly higher mortality for youth and young adults with ASD, ID, or CP compared to the general population for most causes of death. Disability mortality is difficult to ascertain via death certificates alone, since ICD-10 codes for ASD, ID, or CP were not listed as a cause of death for most cases.

Meaning:

These results could inform strategies to prevent excess mortality among people with developmental disabilities.

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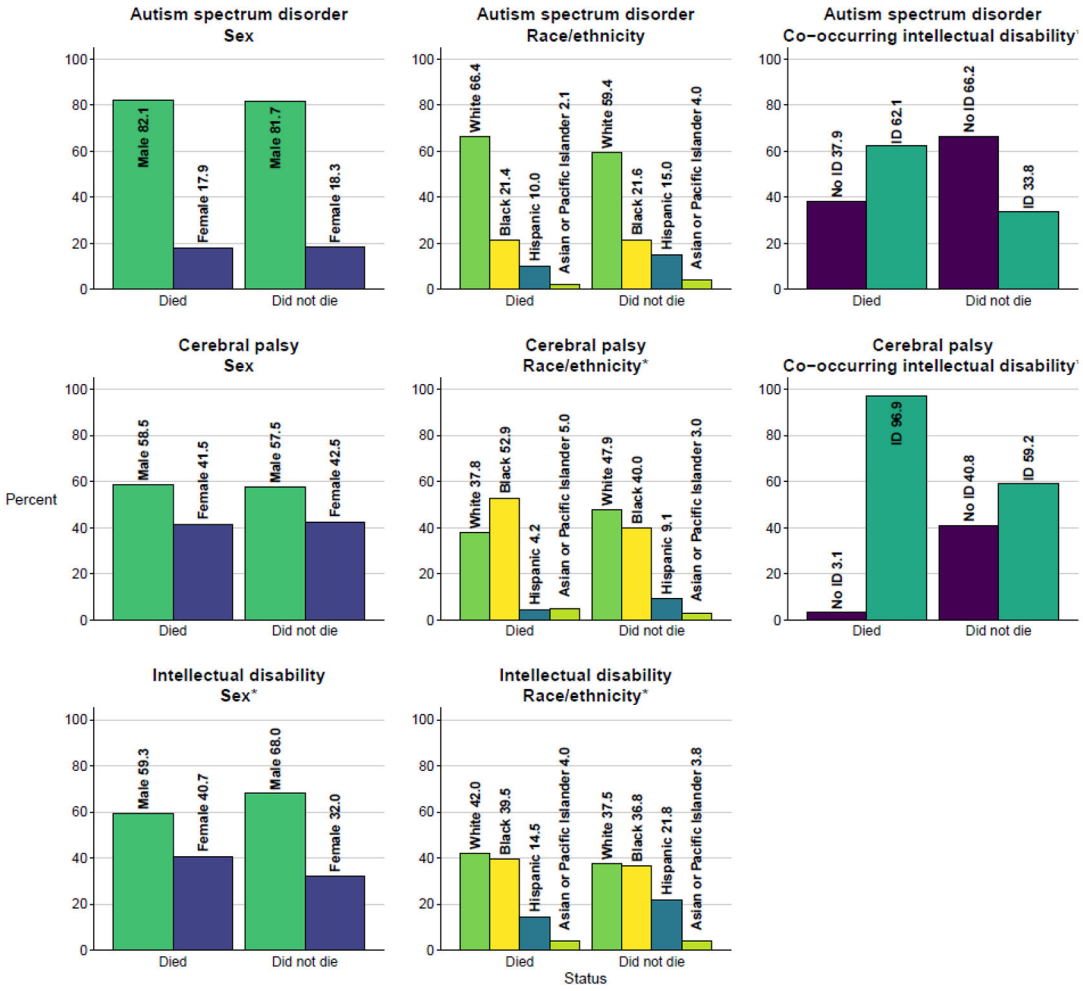


Figure 1.

Characteristics of people with autism spectrum disorder, cerebral palsy, and intellectual disability (ID) who died compared to those who did not die between age 8 and 29 years. Note: Asterisks denote significant difference between those who died or were alive at end of follow-up period. Autism spectrum disorder (ASD) by co-occurring intellectual disability (ID) Pearson chi-square p<0.001. Cerebral palsy (CP) by race/ethnicity Fisher exact p=0.008. CP by co-occurring ID Pearson chi-square p<0.001. ID by sex Pearson chi-square p=0.002. ID by race/ethnicity Pearson chi-square p=0.03. Co-occurring ID status for individuals with ID is not applicable.

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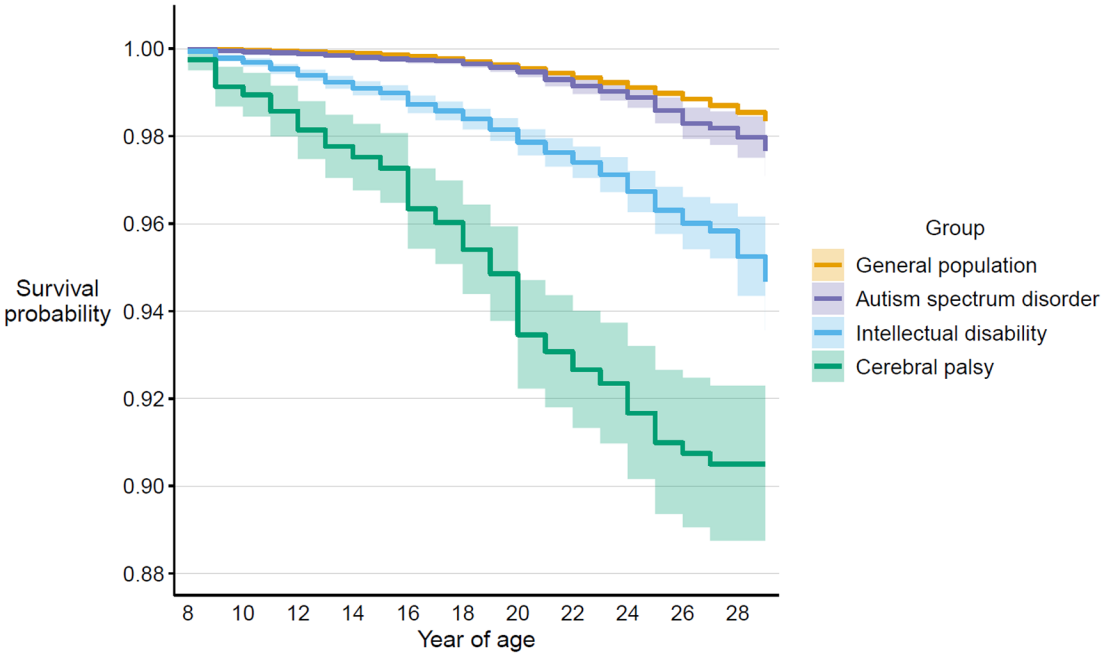


Figure 2.
Cumulative survival from ages 8 through 29 years among the general population and case groups.

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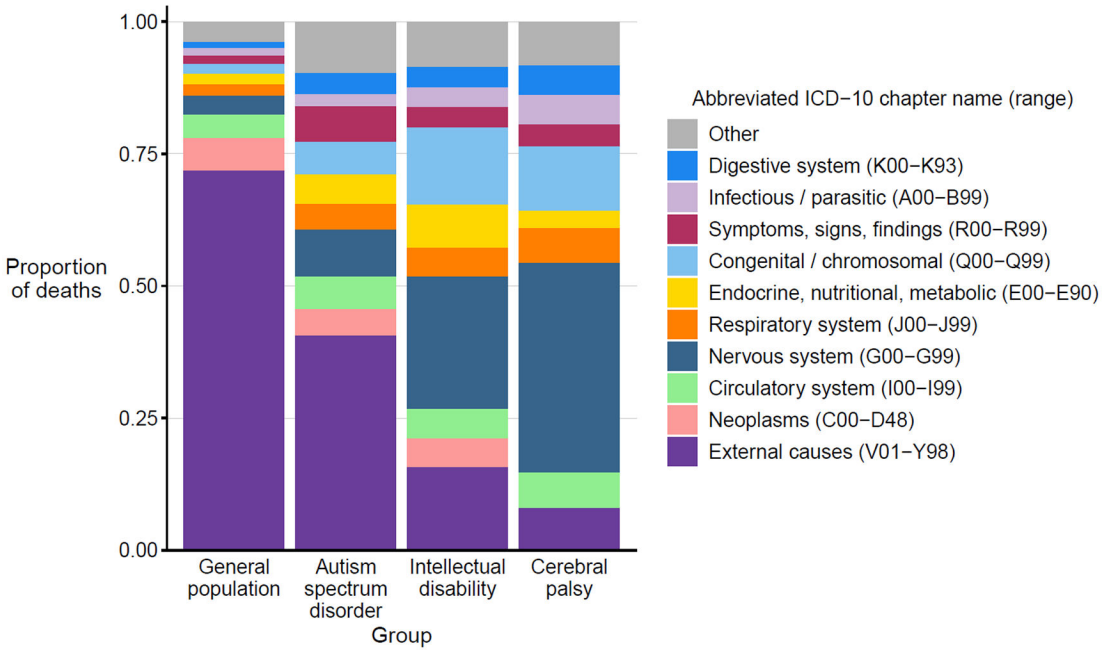


Figure 3.

Proportion of underlying causes of death from top ten most common ICD-10 code chapters among the general population and case groups.

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Table 1.

Cox proportional hazards ratios (HRs) and 95% CIs for ICD-10 chapters as underlying or any (underlying or contributing) cause of death for case groups compared to general population data.

	Underlying cause HR (95% CI)			Any cause HR (95% CI)		
Abbreviated ICD-10 chapter name (ICD-10 code range)[a]	**Autism spectrum disorder**	**Intellectual disability**	**Cerebral palsy**	**Autism spectrum disorder**	**Intellectual disability**	**Cerebral palsy**
Infectious / parasitic (A00-B99)	–	11.56 (6.36-21.03)[b]	41.43 (19.64-87.39)[b]	2.81 (1.63-4.86)[b]	12.14 (8.64-17.07)[b]	32.49 (19.85-53.19)[b]
Neoplasms (C00-D48)	0.92 (0.44-1.94)	3.27 (1.97-5.43)[b]	–	1.00 (0.50-2.00)	3.51 (2.17-5.65)[b]	–
Blood / blood-forming organs (D50-D89)	–	–	–	–	5.35 (2.39-11.96)[b]	–
Endocrine, nutritional, metabolic (E00-E90)	3.60 (1.79-7.23)[b]	17.05 (11.25-25.85)[b]	–	3.08 (1.85-5.12)[b]	10.49 (7.35-14.97)[b]	14.12 (7.05-28.28)[b]
Mental and behavioral (F00-F99)	9.04 (4.02-20.33)[b]	17.41 (8.20-36.94)[b]	–	2.32 (1.57-3.44)[b]	3.64 (2.44-5.44)[b]	4.74 (2.26-9.94)[b]
Nervous system (G00-G99)	3.10 (1.79-5.36)[b]	28.28 (22.29-35.89)[b]	114.57 (86.07-152.49)[b]	3.02 (2.05-4.45)[b]	22.03 (18.27-26.57)[b]	85.15 (67.66-107.16)[b]
Circulatory system (I00-I99)	1.87 (0.97-3.61)	5.47 (3.34-8.95)[b]	14.62 (7.30-29.29)[b]	2.27 (1.58-3.25)[b]	10.21 (8.20-12.71)[b]	22.37 (15.88-31.52)[b]
Respiratory system (J00-J99)	2.59 (1.23-5.44)[b]	9.15 (5.49-15.25)[b]	29.60 (14.75-59.41)[b]	2.48 (1.67-3.68)[b]	14.91 (12.10-18.38)[b]	35.52 (25.79-48.92)[b]
Digestive system (K00-K93)	4.73 (2.11-10.60)[b]	14.36 (7.89-26.16)[b]	49.30 (23.35-104.11)[b]	3.62 (1.94-6.75)[b]	16.17 (11.02-23.73)[b]	56.61 (35.02-91.51)[b]
Musculoskeletal / connective tissue (M00-M99)	–	–	–	–	15.19 (7.82-29.51)[b]	48.56 (20.05-117.60)[b]
Genitourinary system (N00-N99)	–	–	–	2.74 (1.14-6.61)[b]	11.72 (6.76-20.31)[b]	–
Perinatal conditions (P00-P96)	–	–	–	–	28.81 (11.63-71.36)[b]	285.79 (131.43-621.43)[b]
Congenital / chromosomal (Q00-Q99)	3.99 (2.07-7.71)[b]	30.84 (22.54-42.18)[b]	71.78 (42.99-119.84)[b]	3.49 (1.97-6.17)[b]	31.27 (24.31-40.23)[b]	64.84 (42.06-99.95)[b]
Symptoms, signs, findings (R00-R99)	5.68 (3.04-10.62)[b]	10.22 (5.63-18.58)[b]	24.51 (10.16-59.14)[b]	4.12 (3.04-5.59)[b]	16.46 (13.51-20.06)[b]	40.04 (29.73-53.92)[b]
External causes (V01-Y98)	0.79 (0.61-1.01)	0.98 (0.73-1.31)	1.06 (0.57-1.98)	0.79 (0.62-1.02)	1.33 (1.04-1.70)[b]	2.50 (1.68-3.73)[b]
Codes for special purposes (U00-U99)	5.21 (2.15-12.58)[b]	8.73 (3.61-21.11)[b]	–	4.42 (1.83-10.67)[b]	7.39 (3.06-17.85)[b]	–

ICD: International Classification of Disease

[a] See eTable 4 for full details

[b] unrounded 95% CI excludes 1

Note: Dash indicates suppression due to <5 deaths in case group.

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Table 2.

Cox proportional hazards ratios (HRs) and 95% CIs for select ICD-10 sub-chapter causes as any (underlying or contributing) cause of death for case groups relative to general population data.

	Any cause HR (95% CI)		
Abbreviated ICD-10 chapter name[a]			
Select sub-chapter causes (ICD-10 code range)	**Autism spectrum disorder**	**Intellectual disability**	**Cerebral palsy**
Mental and behavioral			
Drug use disorders (F11-16, F18-19, X41-42, X44)	0.82 (0.45-1.48)	–	–
Nervous system			
Epilepsy (G40-G41)	8.85 (4.86-16.14)[b]	22.51 (13.83-36.63)[b]	60.21 (29.87-121.35)[b]
Circulatory system			
Cardiac arrest (I46)	2.77 (1.63-4.68)[b]	17.27 (13.13-22.71)[b]	42.18 (27.94-63.67)[b]
External causes			
Unintentional injury			
Transport accidents (V01-V99, Y85)	0.45 (0.24-0.84)[b]	0.59 (0.30-1.19)	–
Non-transport accidents (W00-X59, Y86)	1.38 (0.94-2.02)	2.68 (1.88-3.82)[b]	5.35 (3.10-9.22)[b]
Accidental poisoning and exposure to noxious substances (X40-X49)	0.77 (0.41-1.43)	–	–
Drownings (W65-W74)	3.34 (1.58-7.03)[b]	5.49 (2.60-11.57)[b]	–
Other accidental threats to breathing (W75-W84)	–	26.32 (15.63-44.33)[b]	88.01 (43.53-177.94)[b]
Intentional injury			
Self-inflicted injuries (suicide) (X60-X84, Y870)	0.90 (0.54-1.49)	–	–
Assault (homicide) (X85-Y09, Y871)	0.45 (0.22-0.95)[b]	1.37 (0.80-2.36)	–
Codes for special purposes			
COVID-19 (U07.1, U07.2, U09.9, U10.9)	4.61 (1.91-11.14)[b]	7.71 (3.19-18.64)[b]	–

ICD: International Classification of Disease

[a] See eTable 4 for full details

[b] unrounded 95% CI excludes 1

Note: Dash indicates suppression due to <5 deaths in case group.