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# Mortality Among Youth and Young Adults With Autism Spectrum Disorder, Intellectual Disability, or Cerebral Palsy

Kelly A. Shaw, PhD; Dedria McArthur, MPH; Deborah A. Bilder, MD; Michelle M. Hughes, PhD; Charles E. Rose, PhD; Amanda V. Bakian, PhD; Maureen S. Durkin, DrPH, PhD; Robert T. Fitzgerald, PhD; Ellen M. Howerton, PhD; Christine Ladd-Acosta, PhD; Maya Lopez, MD; Elise T. Pas, PhD; Walter Zahorodny, PhD; Monica DiRienzo, MA; Mary E. Patrick, MPH; Zachary Warren, PhD; Anita Washington, MPH; Allison Hudson, BS; Sydney Pettygrove, PhD; Josephine Shenouda, DrPH; Matthew J. Maenner, PhD

**IMPORTANCE** Autism spectrum disorder (ASD), intellectual disability (ID), and cerebral palsy (CP) are lifelong neurodevelopmental conditions accompanied by varying impairments. US 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 with the general population through youth or young adulthood.

**DESIGN, SETTING, AND PARTICIPANTS** Nine US 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 through 2016 by 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 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) *International Statistical Classification of Diseases and Related Health Problems, Tenth 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 1612 people with CP. Increased mortality compared with 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 with females in the general population. The distribution of causes of death varied across groups. The most common underlying cause of death *ICD-10* chapters were 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-10* chapter hazard of death that was not elevated for ID and CP compared with 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 subchapter 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** In this study, individuals with ASD, ID, or CP experienced higher mortality from a range of causes compared with 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 health care strategies to understand and prevent health disparities and excess mortality associated with developmental disabilities.

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Supplemental content

**Author Affiliations:** Author affiliations are listed at the end of this article.

**Corresponding Author:** Kelly A. Shaw, PhD, National Center on Birth Defects and Developmental Disabilities, US Centers for Disease Control and Prevention, 4770 Buford Hwy, Atlanta, GA 30341-3717 (nrb7@cdc.gov).

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 nonprogressive movement disorder causing activity limitation and attributed to damage to the developing fetal or infant brain.[2] In the US, more than 3% of children are diagnosed with ASD,[3,4] 1% to 2% with ID,[5,6] and 0.3% with CP.[7,8] These conditions often overlap, eg, 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 with 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 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 3 groups and to the general population.

### 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 with the general population?

**Findings** This population-based cross-sectional study found significantly higher mortality for youth and young adults with ASD, ID, or CP compared with the general population for most causes of death. Disability mortality is difficult to ascertain via death certificates alone, since *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision* 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.

## Methods

ADDM Network site staff accessed health and education records as authorized under 45 Codes of Federal Regulation Part 46 and 34 Codes of Federal Regulation 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 guidelines.

### 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 through 2016 at 9 sites (Arizona, Arkansas, Georgia, Maryland, Missouri, New Jersey, Tennessee, Utah, and Wisconsin) or CP from 2000 through 2010 at 3 sites (Georgia, Missouri, and Wisconsin) (eMethods in Supplement 1). 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 in Supplement 1) and education records were not available at all sites. Sex and race and ethnicity were collected from abstracted records or birth certificates. Race and 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 in Supplement 1); 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.

### NCHS National Vital Statistics System General Population and Counts

Population denominators from National Vital Statistics System (NVSS)[54] and deaths from NVSS Detailed Mortality restricted-use data files for 2000 through 2021 were matched to participating ADDM Network sites and ages for each cohort from 2000 through 2021[55] (eTable 2 and eTable 3 in Supplement 1). Case group death and population counts were not removed from the general population data.

### *International Classification of Diseases and Related Health Problems, Tenth Revision* Cause of Death Codes

*International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (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 (eTable 4 in Supplement 1 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 (eg, 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 in Supplement 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 in Supplement 1). Of the 32 787 individuals submitted to NDI, most (81.1%) had 1 condition, 17.0% had ASD and ID, 1.4% had CP and ID, 0.2% had ASD and CP, and 0.2% had all 3 conditions (eFigure 1 in Supplement 1). Pearson $\chi^2$ 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 and ethnicity, and co-occurring ID (for ASD and CP). Individuals with missing data (or other race and ethnicity) were excluded from analyses stratified by that variable (sex missing for <0.1% ID, race and 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 $\chi^2$ or Fisher exact tests were considered significant when $P < .05$. 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 1 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 in Supplement 1). For causes of death, hazards were calculated for case groups with 5 or more deaths from that cause. HRs were considered significant when the unrounded 95% 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] We used R version 4.5.0 (The R Project.)

## Results

The study included 23 393 people with ASD (among those with available data, sex: 81.7% male and 18.3% female; race and ethnicity: 4.0% Asian or Pacific Islander, 21.6% Black, 15.0% Hispanic, and 59.5% White), 14 031 people with ID (among those with available data, sex: 67.8% male and 32.2% female; race and ethnicity: 3.8% Asian or Pacific Islander, 36.9% Black, 21.7% Hispanic, and 37.6% White), and 1612 people with CP (among those with available data, sex: 57.6% male and 42.4% female; race and ethnicity: 3.2% Asian or Pacific Islander, 41.0% Black, 8.8% Hispanic, and 47.1% White) (eTable 6 in Supplement 1). 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 in Supplement 1).

### Characteristics of Individuals in Case Groups Who Died and Those Who Did Not Die

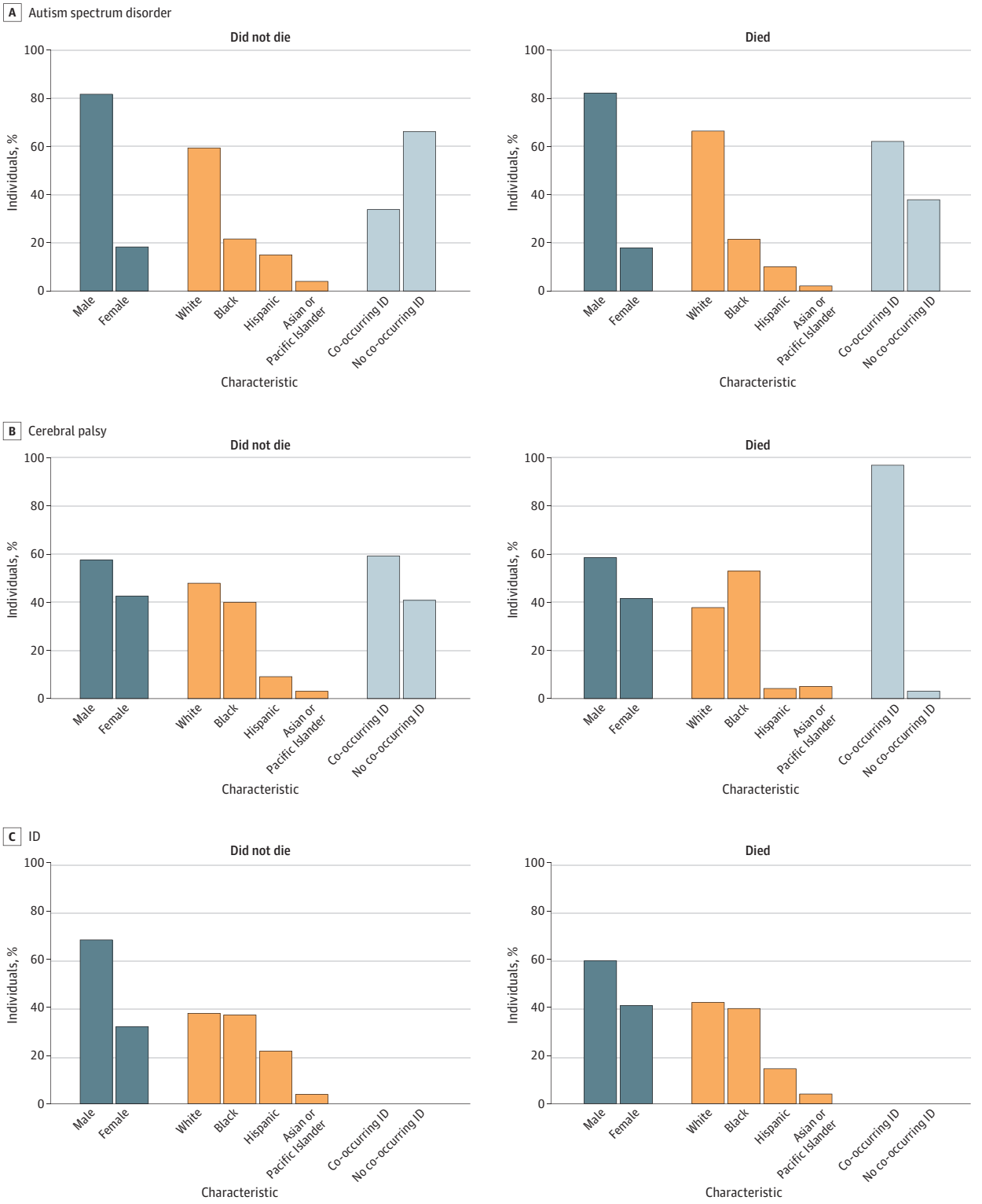
Complete demographic data for case groups overall and stratified by those who died and did not die between age 8 and 29 years is available in eTable 6 in Supplement 1. Individuals who died and those who did not die had similar distribution of sex for ASD (82.1% and 17.9% female, and 81.7% male and 18.3% female, respectively; $P = .99$) and CP (58.5% and 41.5% female, and 57.5% male and 42.5% female, respectively; $P = .90$), but there was a lower percentage of males among those with ID who died compared with those who did not die (59.3% male and 40.7% female, and 68.0% male and 32% female, respectively; $P = .002$) (**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 with 33.8%; $P < .001$) and CP (96.9% compared with 59.2%; $P < .001$).

### 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 in Supplement 1). 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 in Supplement 1).

For individuals with ASD, sex-specific mortality was similar to the general population for males with and without

Figure 1. Characteristics of People With Autism Spectrum Disorder, Cerebral Palsy, and Intellectual Disability (ID) Who Did Not Die Compared With Those Who Died Between Ages 8 and 29 Years




Comparisons between those who did not die or who died by the end of follow-up period were significantly different for: autism spectrum disorder by co-occurring D (Pearson $\chi^2$, $P < .001$), cerebral palsy by race and ethnicity (Fisher exact, $P = .008$), cerebral palsy by co-occurring ID (Pearson $\chi^2$, $P < .001$), ID by sex (Pearson $\chi^2$, $P = .002$), and ID by race and ethnicity (Pearson $\chi^2$, $P = .03$). Co-occurring ID status for individuals with ID is not applicable.

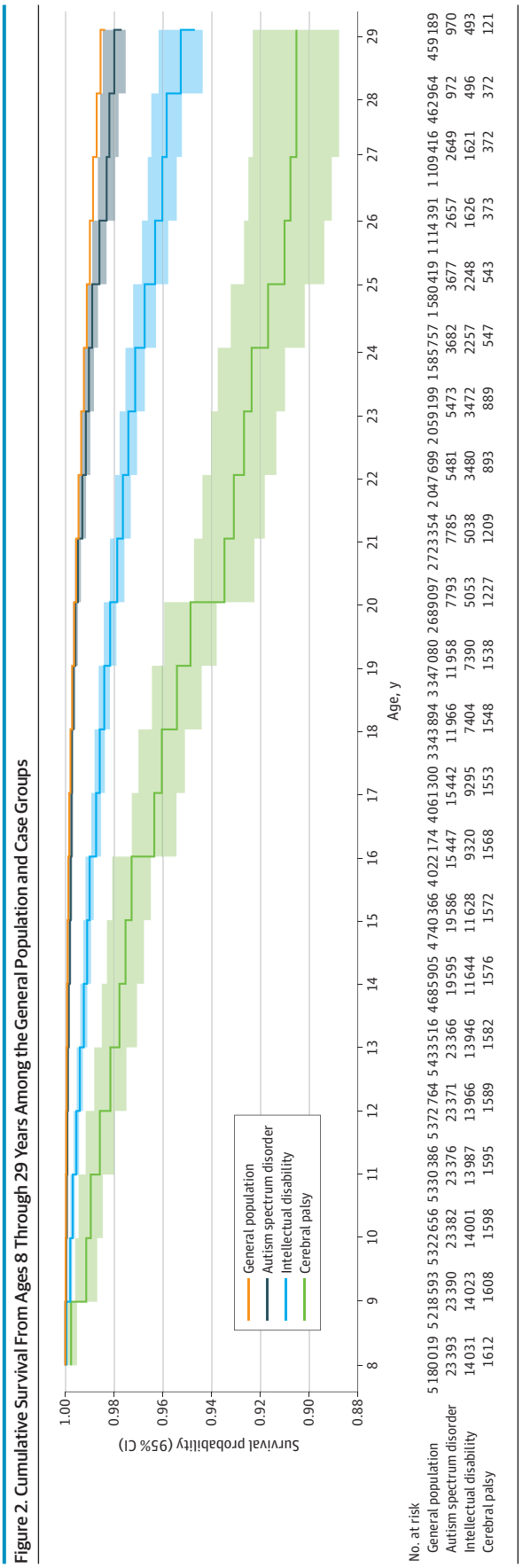



Figure 2. Cumulative Survival From Ages 8 Through 29 Years Among the General Population and Case Groups

co-occurring ID and females without co-occurring ID (eTable 5 in Supplement 1). 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 with 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 in Supplement 1). 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

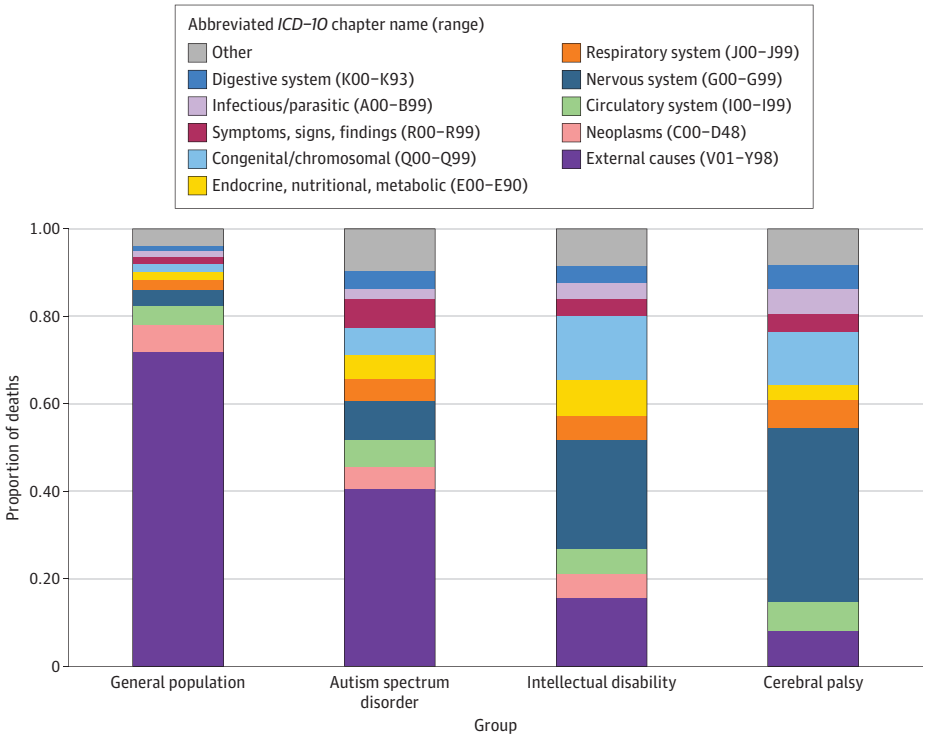
For *ICD-10* code chapters with 5 or more deaths in the ASD group, individuals with ASD experienced higher mortality from 8 of 11 chapters as underlying cause (HRs from 2.59 to 9.04) and 11 of 13 *ICD-10* code chapters as any cause of death (HRs from 2.27 to 4.42) compared with the general population (**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 with the general population for *ICD-10* code chapters with 5 or more 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 with 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 5 Deaths From the Subchapter Cause

Compared with the general population, mortality from transport injuries 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 with the general population, the group with ASD had similar mortality from nontransport injuries 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 nontransport injuries, those with ASD

Figure 3. Proportion of Underlying Causes of Death From Top 10 Most Common *International Statistical Classification of Diseases, Tenth Revision (ICD-10)*, Code Chapters Among the General Population and Case Groups.




and ID had elevated mortality from death from unintentional drowning and submersion (ASD: HR, 3.34; 95% CI, 1.58-7.03 and ID: HR, 5.49; 95% CI, 2.60-11.57) compared with the general population. Of 7 ASD drowning deaths, 4 occurred in a swimming pool and 3 in a bathtub. Of 7 ID drowning deaths, 4 occurred in a swimming pool, 1 in a bathtub, and 2 in natural water. Mortality from other unintentional 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 with the general population. Within this group, 14 of 15 ID deaths and all 8 CP deaths were from other or unspecified objects, with food specified as the cause of 1 ID death. For individuals with ASD, mortality from unintentional 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 with the general population.

The hazard of death from drug use disorders was similar for individuals with ASD compared with the general population. Mortality from epilepsy was elevated compared with 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 with 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 with 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 underascertained 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 with the general population. Many studies have found higher mortality for females

Table 1. Cox Proportional Hazards Ratios (HRs) and 95% CIs for *International Statistical Classification of Diseases, Tenth Revision* (*ICD-10*) Chapters as Underlying or Any (Underlying or Contributing) Cause of Death for Case Groups Compared With General Population Data

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

Abbreviation: NA, not applicable.

[a] See eTable 4 in Supplement 1 for full details.

[b] Indicates suppression due to less than 5 deaths in case group.

[c] Unrounded 95% CI excludes 1.

with ID[23,25-28,32-34] or ASD and ID[18,20] compared with 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 lacked sufficient evidence.[63]

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 and ethnicity compared with 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 unintentional 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 with 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]

Table 2. Cox Proportional Hazards Ratios (HRs) and 95% CIs for Select *International Statistical Classification of Diseases, Tenth Revision (ICD-10)* Subchapter Causes as Any (Underlying or Contributing) Cause of Death for Case Groups Relative to General Population Data

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

Abbreviation: NA, not applicable.

[a] See eTable 4 in Supplement 1 for full details.

[b] Indicates suppression due to less than 5 deaths in case group.

[c] Unrounded 95% CI excludes 1.

Reduced transport injury 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 injury 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, eg, 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 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 with 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 multidisability 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 with the general popula-

tion. 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. Death 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 health care strategies could help prevent disparities in mortality associated with developmental disabilities.

## ARTICLE INFORMATION

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**Author Affiliations:** National Center on Birth Defects and Developmental Disabilities, US Centers for Disease Control and Prevention, Atlanta, Georgia (Shaw, McArthur, Hughes, Rose, DiRienzo, Patrick, Washington, Maenner); University of Utah Huntsman Mental Health Institute, Salt Lake City (Bilder, Bakian); University of Wisconsin, Madison (Durkin); Washington University in St Louis School of Medicine, St Louis, Missouri (Fitzgerald); Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland (Howerton, Ladd-Acosta, Pas); University of Arkansas for Medical Sciences, Little Rock (Lopez, Hudson); Rutgers New Jersey Medical School, Newark (Zahorodny, Shenouda); Vanderbilt University Medical Center, Nashville, Tennessee (Warren); University of Arizona, Tucson (Pettygrove).

**Author Contributions:** Dr Shaw had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.
*Concept and design:* Shaw, Bilder, Hughes, Rose, Washington, Maenner.
*Acquisition, analysis, or interpretation of data:* Shaw, McArthur, Hughes, Rose, Bakian, Durkin, Fitzgerald, Howerton, Ladd-Acosta, Lopez, Pas, Zahorodny, DiRienzo, Patrick, Warren, Hudson, Pettygrove, Shenouda-Boutros, Maenner.
*Drafting of the manuscript:* Shaw, Bilder, DiRienzo, Maenner.
*Critical review of the manuscript for important intellectual content:* All authors.
*Statistical analysis:* Shaw, McArthur, Hughes, Rose, Bakian, Hudson, Maenner.
*Obtained funding:* Bakian, Durkin, Ladd-Acosta, Pettygrove.
*Administrative, technical, or material support:* McArthur, Hughes, Durkin, Fitzgerald, Howerton, Pas, Zahorodny, DiRienzo, Warren, Washington, Hudson, Pettygrove, Maenner.
*Supervision:* Hughes, Durkin, Patrick, Hudson, Pettygrove, Maenner.

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