Centers for Disease Control and Prevention

Congenital Heart Defects (CHDs)

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Data and Statistics on Congenital Heart Defects

Congenital heart defects (CHDs) are the most common types of birth defects, and babies born with these conditions are living longer and healthier lives. Find more statistics about CHDs below.

Number of U.S. Babies Born with CHDs

- CHDs affect nearly 1% of—or about 40,000—births per year in the United States.[1,2]
- The prevalence (the number of babies born with heart defect compared to the total number of births) of some CHDs, especially mild types, is increasing, while the prevalence of other types has remained stable. The most common type of heart defect is a ventricular septal defect (VSD).[3,4]
- About 1 in 4 babies with a CHD have a critical CHD. Infants with critical CHDs generally need surgery or other procedures in their first year of life. [Read summary]
- The prevalence of all types of CHDs, including critical CHDs, varies by state and by type of defect. [Read summary]

Did You Know?

CDC is working with the University of Arizona, Duke University, Emory University, the New York State Department of Health, the South Carolina Department of Health and Environmental Control, the University of Utah, and the University of Iowa to follow individuals with CHDs across the lifespan. Understanding health issues and needs across the lifespan is vital to improving the lives of individuals born with these conditions. [Learn More]

Number of U.S. Children and Adults Living with CHDs

- Currently, there are several state-based birth defects programs that follow CHDs among newborns and young children, but no system exists to look at the growing population of older children and adults with heart defects.
- To date, other methods have been used to estimate the total number of children and adults with these defects. For example, one study estimated that, in 2010, over 2 million infants, children, adolescents, and adults were living with CHDs in the United States. Researchers estimated that about 1 million U.S. children and about 1.4 million U.S. adults were living with CHDs. Overall, there are slightly more adults living with CHDs than children. To obtain this estimate, researchers used data from administrative healthcare databases in Canada to estimate the prevalence of people living with CHDs and applied this to the U.S. Census data from 2010. [Read abstract]

CHD-Related Deaths

- CHDs are a leading cause of birth defect-associated infant illness and death. [Read article]
- Infant deaths due to CHDs often occur when the baby is less than 28 days old (sometimes called the neonatal period). In a study of neonatal deaths, 4.2% of all neonatal deaths were due to a CHD. [Read article]
- During 1999–2006, there were 41,494 deaths related to CHDs in the United States. This means that CHDs were either the main cause of death or contributed to death in some way. During this period, CHDs were listed as the main cause of

death for 27,960 people. Nearly half (48%) of the deaths due to CHDs occurred during infancy (younger than 1 year of age). [Read article]

Survival

Survival of infants with CHDs depends on how severe the defect is, when it is diagnosed, and how it is treated. [Read summary]

- Through infancy:
  - About 97% of babies born with a *non-critical* CHD are expected to survive to at least one year of age.
  - About 75% of babies born with a *critical* CHD are expected to survive to at least one year of age.
  - Survival and medical care for babies with critical CHDs are improving.
    - Between 1979 and 1993, about 67% of infants with *critical* CHDs survived to at least one year.
    - Between 1994 and 2005, about 83% of infants with *critical* CHDs survived to at least one year.
- Through adolescence:
  - About 95% of babies born with a *non-critical* CHD are expected to survive to at least 18 years of age.
  - About 69% of babies born with *critical* CHDs are expected to survive to at least 18 years of age.
- Through young adulthood:
  - About 81% of babies born with *critical* or *non-critical* CHDs are expected to survive to at least 35 years of age. [Read summary]
    - After the first year of life, about 93% of one-year-olds with a CHD are expected to survive to at least 35 years of age.
  - Survival to young adulthood is still lower for people with CHDs than the general population. The complexity of their defect, presence of other birth defects and birthweight might impact their survival to young adulthood. In addition, the race and ethnicity of their mother might have contributed to survival, which suggests that various factors at multiple levels might play a role, including access to care, systemic racism, and implicit bias. People with CHDs may benefit from more monitoring to identify and care for medical concerns earlier in life.

Illness and Disability

- About 4 in every 10 adults with a CHD have a disability, with cognitive disabilities (trouble concentrating, remembering, or making decisions) being the most common type. [Read Summary] [Read key findings]
- At least 15% of CHDs are associated with genetic conditions.[5,6]
- About 20% to 30% of people with a CHD have other physical problems or developmental or cognitive disorders.[7,8,9]
- Children with CHD are about 50% more likely to receive special education services compared to children without birth defects.[10]
- The occurrence and severity of a developmental disability or delay increases with how complex the heart defect is. For example, more than 80% of individuals with a mild CHD have no developmental disabilities. However, more than half of those with a more critical type of CHD have some form of disability or impairment. Guidelines for screening, diagnosing, and managing developmental disabilities or delay in children with CHDs have been developed. [Read summary]
- Parents of children with special healthcare needs with heart problems, including CHDs, commonly report that their children's condition prevents them from doing things other children do. Parents reported that these children experience more difficulty with learning, concentration, communication, self-care, and fine and gross motor skills than children with special healthcare needs without heart problems. These children also missed more days of school and participated less in extracurricular activities than children with special healthcare needs without heart problems[11]. [Read summary]
- Compared to children without a heart condition, children with a heart condition were more likely to have special healthcare needs, including medication needs, physical or speech therapy, and treatment for developmental or

behavioral problems. Nearly 60% of children with a current heart condition have special healthcare needs, compared to 20% of children without a heart condition[12]. [Read summary]

Costs

- In the United States, hospital costs for the population of individuals with cardiovascular defects in 2013 were about $6.1 billion. Critical CHD–associated hospitalizations had the highest mean and median cost of the birth defect categories considered ($79,011 and $29,886, respectively). [Read summary [265 KB / 6 pages]]
- Pediatric hospitalizations with CHDs accounted for approximately $5.6 billion in hospital costs, representing 15.1% of costs for all pediatric hospitalizations in 2009. Hospitalizations with critical CHD accounted for 26.7% of all costs for CHD hospitalizations, with hypoplastic left heart syndrome, coarctation of the aorta, and tetralogy of Fallot having the highest total costs. [Read summary]
- In addition to the medical costs of care for CHDs, families of children with CHDs can face other costs, such as high out-of-pocket expenses, financial problems, greater care-giving hours, quitting or reducing hours at work in order to care for their child, and decreased mental health. [Read summary]

Highlighted Articles

Key Findings | Feature Articles

Children with Heart Conditions Have Special Healthcare Needs

A study from the Centers for Disease Control and Prevention (CDC) found that 1 in 77 U.S. children reportedly had a current heart condition in 2016.
(Published: September 27, 2018)

Study Finds Infant Cardiac Deaths Have Declined in States that Mandate Screening for Critical Congenital Heart Disease

The *Journal of the American Medical Association* has published a study reporting a more than 33% decline in infant deaths from critical congenital heart disease (CCHD) in eight states that mandated screening for CCHD using pulse oximetry compared to states without screening policies
(Published: December 5, 2017)

Estimating the Number of People with Congenital Heart Defects Living in the United States

The journal *Circulation* has published a study that estimates about 1 million children and 1.4 million adults in the United States were living with a congenital heart defect (CHD) in 2010.
(Published: July 5, 2016)

Use of Special Education Services among Children with CHDs

CDC study findings in *Pediatrics* show that children with congenital heart defects (CHDs) received special education services more often than children without birth defects.
(Published: August 17, 2015)

Estimated Number of Infants Detected and Missed by Critical Congenital Heart Defect Screening

The journal *Pediatrics* has published a study estimating the number of infants with critical congenital heart defects(critical CHDs) potentially detected or missed through universal screening for critical CHDs using pulse oximetry.
(Published: May 11, 2015)

Diabetes before pregnancy and congenital heart defects

In a study published in the *American Journal of Preventative Medicine*, women with diabetes before pregnancy were about 4 times more likely to have a pregnancy affected by a congenital heart defect compared to women without diabetes.
(Published: February 2015)

Long Term Outcomes in Children with Congenital Heart Disease

In a study published in the *Journal of Pediatrics*, CDC researchers found that children with CHD are more likely to report worse health overall, to need more healthcare services, and to have other health conditions, compared to children without CHD.
(Published: January 2015)

Infant Death Due to Heart Defects

Congenital heart defects are conditions present at birth that can affect the way the heart works. They can cause lifelong disability or death. They are the most common type of birth defect, affecting nearly 40,000 births in the United States each year.
(Published: July 9, 2014)

Living with a Heart Defect

Learn about congenital heart defects and about Mary, an adult living with this condition.
(Published: February 12, 2018)

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Last Reviewed: August 15, 2023