

Children with heart defects need early evaluation for related disorders

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Children born with a congenital heart defect should receive early evaluation, prompt treatment and ongoing follow-up for related developmental disorders affecting brain function, according to a new American Heart Association scientific statement published in *Circulation*.

Each year in the United States, congenital [heart](#) defects — present at birth — affect approximately 36,000 infants, or nine out of every 1,000. Adult survivors now number between 1 and 3 million.

Medical advances help most infants born with a congenital heart defect survive into adulthood. However, survivors with complex heart problems are at a greater risk for developmental issues compared to heart-healthy children, which may stem from the heart defect, an underlying genetic variation, medical treatments or the day-to-day psychological stress of living with an ongoing, serious disease.

"If your child fits the high-risk criteria, go to the physician who coordinates your child's care to obtain evaluations for neurodevelopmental, psychosocial, and behavioral and emotional issues," said Bradley S. Marino, M.D., M.P.P., M.S.C.E., co-chair for the scientific statement's writing group and associate professor of pediatrics at the University of Cincinnati College of Medicine.

"Your child's cardiologist should continue to handle the physical issues related to your child's heart disease, but other caregivers need to join

your child's 'medical home' to ensure the best ongoing, comprehensive care," said Marino who is also director of the Heart Institute Research Core and the Heart Institute Neurodevelopmental Clinic at Cincinnati Children's Hospital Medical Center. A medical home is usually the child's primary care provider.

Developmental disorders among children with congenital heart defects may manifest in childhood or adolescence as school difficulties, poor social skills, speech and language problems, attention, behavior and emotional issues and physical limitations. These developmental disorders can be identified and managed through continuous surveillance, appropriate screening, early evaluation, periodic re-evaluation, and continuous, comprehensive treatment coordinated by a central care provider. Treatment may include special education classes, tutoring, psychological, physical, and occupational and speech therapies.

In addition to assessing risk level and referring high-risk patients for further developmental and medical evaluation, other recommendations include:

- Establish a "medical home," usually the primary care provider, to coordinate care between various specialists.
- Each time your child visit's their "medical home," their risk of developmental disorders should be reassessed because risk level may change over time.
- If your child is considered at high-risk, they may be referred for early intervention even before a developmental disorder is formally diagnosed.
- For children with congenital heart disease deemed high-risk, periodic re-evaluation for developmental disorders is recommended throughout infancy and childhood at 12 to 24 months, 3 to 5 years and 11-12 years of age.

- If your child is high-risk, they may benefit from higher-education or vocational counseling when they are a young adult.

The statement identifies, for the first time, conditions that increase the risk for these developmental disorders among survivors, including open heart surgery in infancy, having a [congenital heart defect](#) that results in the child being chronically "blue", or a combination of congenital heart disease and one of the following issues: premature birth; developmental delay as a baby; suspected genetic abnormality or syndrome; history of mechanical support to help the heart; heart transplantation; a history of cardiopulmonary resuscitation; prolonged hospitalization during the child's heart care; seizures related to heart surgery; and brain abnormalities noted on brain imaging.

"If we identify developmental problems earlier, we're going to help prevent issues from coming up in school that prevent these children from achieving their fullest potential," Marino said. "In the past, we were happy if they survived. Now, we want them to survive and thrive."

Provided by American Heart Association

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