

About CH STRONG

During the past 7 years, three teams (University of Arizona College of Medicine, University of Arkansas for Medical Sciences, and the March of Dimes) in partnership with the Centers for Disease Control and Prevention worked together on CH STRONG, the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG. Together, they gathered vital information to improve the lives of individuals with heart defects. We thank everyone who provided information for CH STRONG.

The previous [CH STRONG Project Update](#) highlighted that young adults with heart defects were 8 times more likely to have a disability than young adults without heart defects. We continue to examine heart defects and co-occurring disabilities. In this issue, we share updates on reproductive health concerns among women with heart defects living with disabilities, and education and employment outcomes among young adults with congenital heart defects and cognitive disabilities.

On the next two pages, we highlight the key findings from the publications.

Site Leads

Karrie Finn Downing, MPH

Centers for Disease Control and Prevention, Atlanta, Georgia

Scott Klewer, MD

University of Arizona College of Medicine, Tucson, Arizona

Wendy Nembhard, PhD, MPH

Arkansas Center for Birth Defects Research and Prevention and the University of Arkansas for Medical Sciences, Little Rock, Arkansas



Inside This Issue

“Reproductive Health Counseling and Concerns Among Women with Congenital Heart Defects With and Without Disabilities” published in the *[Journal of Women's Health](#)*

“Healthcare and Socioeconomic Outcomes Among Young Adults With Congenital Heart Defects and Functional Cognitive Disabilities, CH STRONG 2016 to 2019” published in *[The American Journal of Cardiology](#)*



Reproductive Health Concerns among Women with Heart Defects with and without Disabilities

Women with heart defects may have a higher risk of pregnancy-related issues; however, with appropriate medical care and treatment, most women with heart defects can have healthy pregnancies.

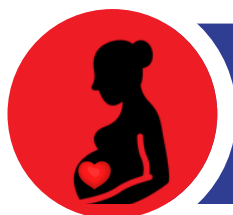
More than 1 in 3 women with heart defects have a disability. Little is known about the reproductive concerns of women with heart defects and disabilities and the reproductive health counseling they receive. Therefore, we examined these topics in CH STRONG.



Compared with young women with heart defects and no disabilities, CH STRONG researchers found that young women with heart defects and disabilities were ...



2 times more likely to delay or avoid pregnancy because of their heart defect.



Less likely to have ever been pregnant.

Women with heart defects can speak with a healthcare provider about their reproductive health concerns to make the best possible choices for their overall health and well-being. With regular medical care and treatment, many women with heart defects can have a healthy pregnancy.

Health Care, Education, and Employment among Young Adults with Congenital Heart Defects and Cognitive Disabilities

Many young adults with heart defects have disabilities, and cognitive disabilities are the most common. People with cognitive disabilities experience serious difficulty concentrating, remembering, or making decisions.

Using CH STRONG, we wanted to learn more about people living with both heart defects and cognitive disabilities.

In a paper titled “Healthcare and Socioeconomic Outcomes Among Young Adults With Congenital Heart Defects and Functional Cognitive Disabilities,” CH STRONG researchers found that ...



Young adults with heart defects and cognitive disabilities often have less education and lower employment than those without disabilities.



Only **3 in 10** young adults with heart defects and cognitive disabilities had ever received disability benefits.



About **4 in 10** young adults with heart defects and cognitive disabilities had not received cardiology care in the past 5 years.



3 in 10 young adults with heart defects and cognitive disabilities delayed health care because of cost.

People living with both heart defects and cognitive disabilities may have unique challenges getting the care they need. Working with your doctor to stay involved in your healthcare decisions, as well as using telemedicine when available, may make health care more affordable and accessible. If you or a loved one has a disability, ask your doctor about community resources, social services, and virtual care options to increase access and meet medical needs.