

Finding The Invisible Child

Childhood Heart Disease and the Global Health Agenda

2nd in a Series
of 4 Briefs from
Children's HeartLink



Access to Care for Children with Heart Disease Means Treatment that is Available, Affordable and of the Highest Quality

This paper focuses on access barriers to pediatric cardiac care. It is the second in a series of four briefs by Children's HeartLink intended to introduce the needs of children with heart disease to a new audience—policy makers, international organizations, donors and others who help implement the global health agenda. The series is available for download at theinvisiblechild.childrensheartlink.org

Every year one million children are born with congenital heart disease¹—heart disease due to an abnormality in the structure of the heart. Another 300,000 school-age children will acquire rheumatic heart disease from untreated Streptococcal A infections. Sadly, for 90 percent of children with heart disease, treatment is either unavailable, unaffordable or of suboptimal quality².

Without appropriate treatment, each year about half of the babies born with significant congenital heart disease will die in infancy or early childhood. A third of them die within the first month of life³—and another 230,000 older children and young adults will succumb to rheumatic heart disease⁴. Others will survive to have their symptoms misdiagnosed as a more common infectious disease, thus delaying life-saving treatment⁵.

Unless a concerted effort is made to support surveillance and treatment, their heart disease will remain invisible to the global health community, prevalence will continue to be underrepresented, and equitable access to pediatric cardiac care will remain under-prioritized within global health systems strengthening efforts.

The Sustainable Development Goals (SDGs) provide an opportunity to change the status of heart disease in children from an invisible disease to one integral to eliminating preventable child deaths. The SDGs implore the world to build upon the good work inspired by the Millennium Development Goals, acknowledging that many regions have seen significant economic and epidemiologic changes since 2000.

Several economies are transitioning from low-income to middle-income countries, and childhood diseases spread by poor sanitation, contaminated water and under-nutrition are being controlled in many parts of the world. In their place, health systems are increasingly burdened with complications arising from noncommunicable and congenital diseases.

At an annual rate of approximately 1:120 live births, congenital heart disease is predictably consistent across populations. In order to achieve the SDG target⁶ of “end[ing] preventable deaths of newborns and children under 5 years of age,” specific accountability measures such as health workforce training and inclusion of pediatric heart disease in universal health coverage must be addressed to ensure that all children have access to pediatric cardiac screening and treatment⁷.

Of the children that are diagnosed with heart disease, their treatment and survival is often better predicted by their location and family income than by the severity of their disease. Higher birth rates and lower economic development mean that the overwhelming global burden of pediatric heart disease falls on the health systems least equipped to deal with it.

Solutions start with recognition of a problem, and right now children with heart disease are mainly invisible as a global health issue.

Health systems will only be able to meet the needs of children with heart disease once the burden of disease is recognized by clinicians, hospital administrators, policy makers and the donor community, and investments are made accordingly.

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Primary Prevention of Acquired Heart Disease

Pediatric heart disease falls into two broad categories: congenital and acquired. While treatment plans for each may be similar, the epidemiology of these diseases has one significant difference: acquired means preventable.

Rheumatic heart disease is the most common—and most preventable—form of acquired heart disease in children and young adults⁸. Rheumatic heart disease occurs in about 60 percent of untreated cases of acute rheumatic fever², which itself results from untreated Streptococcal A infections. Antibiotic treatment of sore throat presenting with Strep A symptoms has been

shown to reduce the onset of acute rheumatic fever by 70 percent; 80 percent if given intramuscularly.

Barriers in access and adherence to care, however, prevent basic antibiotic treatment. As a result, 300,000 new cases of rheumatic heart disease occur each year, almost exclusively in developing countries². One-third to one-half of all cardiac hospital admissions in developing countries are due to rheumatic heart disease. It is responsible for 10 percent of maternal deaths, and is the main predisposing factor for infection in the lining of the heart or heart valves⁹. Without treatment, 20 percent of children with rheumatic heart disease will be dead by the age of 15 and more than 70 percent by 25 years⁸.

At least 15.6 million people are estimated to be currently affected by rheumatic heart disease, with a significant number requiring weeks-long hospitalization and heart surgery in the next five to 20 years¹⁰. The economic burden due to disability and premature loss of life is great, but it is preventable.

Clearly, the prevention and control of acute rheumatic fever/rheumatic heart disease in developing countries will only be accomplished as it was in developed countries—through primary health care efforts to improve the environmental, social and economic conditions of populations at risk, and timely use of antibiotics¹¹. This is a strategy that can, if made a priority by countries, policy makers and donors, realistically be incorporated into most health systems.

Overcoming Barriers in Access to Care

Barriers that limit availability and affordability, or erode trust in the quality of treatment affect when and how—or if—people seek care for their children¹².

Limited access to care in low- and middle-income countries is well documented. With few exceptions, children who receive care from a hospital or clinic are more likely to come from wealthier families, have parents with higher levels of education and live in urban areas¹³. Due to marginalization of children’s cardiovascular health on the global development agenda, no reliable data exist specifically for children with heart disease, but it is reasonable to presume that disparities in access are the same at the primary level and worse for specialist care.

Availability of Care

It is not easy to see a health care worker if there are none where you live. The dramatic global shortage of health care workers means that only 51-64 percent of women and their newborns in low- and middle-income countries receive skilled care at or immediately following birth¹⁴. In the absence of universal screening guidelines, those that do are not likely screened for congenital heart disease. This oversight is not exclusively the problem of developing countries with weak health systems. The occurrence of undiagnosed cases of congenital heart disease is reported to be as high as 1:3,500 births in high-income countries with universal health care¹⁵. The rate of un- or misdiagnosed congenital heart disease in countries with inadequate access to care can reasonably be assumed to be magnitudes higher.

A silo approach to health care delivery will not meet the needs of the children with complicated and chronic health conditions like heart disease. Scaling up specialist pediatric cardiac care requires a functional

health system with an integrated referral network of community health workers, community clinics, regional hospitals and specialized care centers, as distributed according to a model like the one below:

Pediatric Cardiac Care in an Ideal Health System*

Capacity	Continuum of Care	Level of Care			
		Village Health Center	First-Level Hospital ^a	Second-Level Hospital ^b	Third-Level Hospital ^c
Prenatal care and attended birth	Early Detection	X	X		
Universal screening and referral	Early Detection	X	X	X	X
National congenital birth anomaly reporting mechanism	Surveillance	X	X	X	X
Antibiotic availability and delivery	Prevention (RHD)	X	X	X	X
Pulse oximeter	Diagnosis	X	X	X	X
Echocardiogram, electrocardiogram, and chest x-ray	Diagnosis		X	X	X
Fetal echocardiogram	Diagnosis			X	X
Cardiac catheterization	Diagnosis & Treatment				X
Cardiac medications availability and delivery	Treatment	X	X	X	X
Spinal and general anesthesia	Treatment		X	X	X
Open heart surgery	Treatment				X
Intensive care unit	Treatment				X
Infection control	Quality Assurance	X	X	X	X
Continuing medical education	Quality Assurance	X	X	X	X

*adapted from *Essential Surgery*, Table 8.5⁵

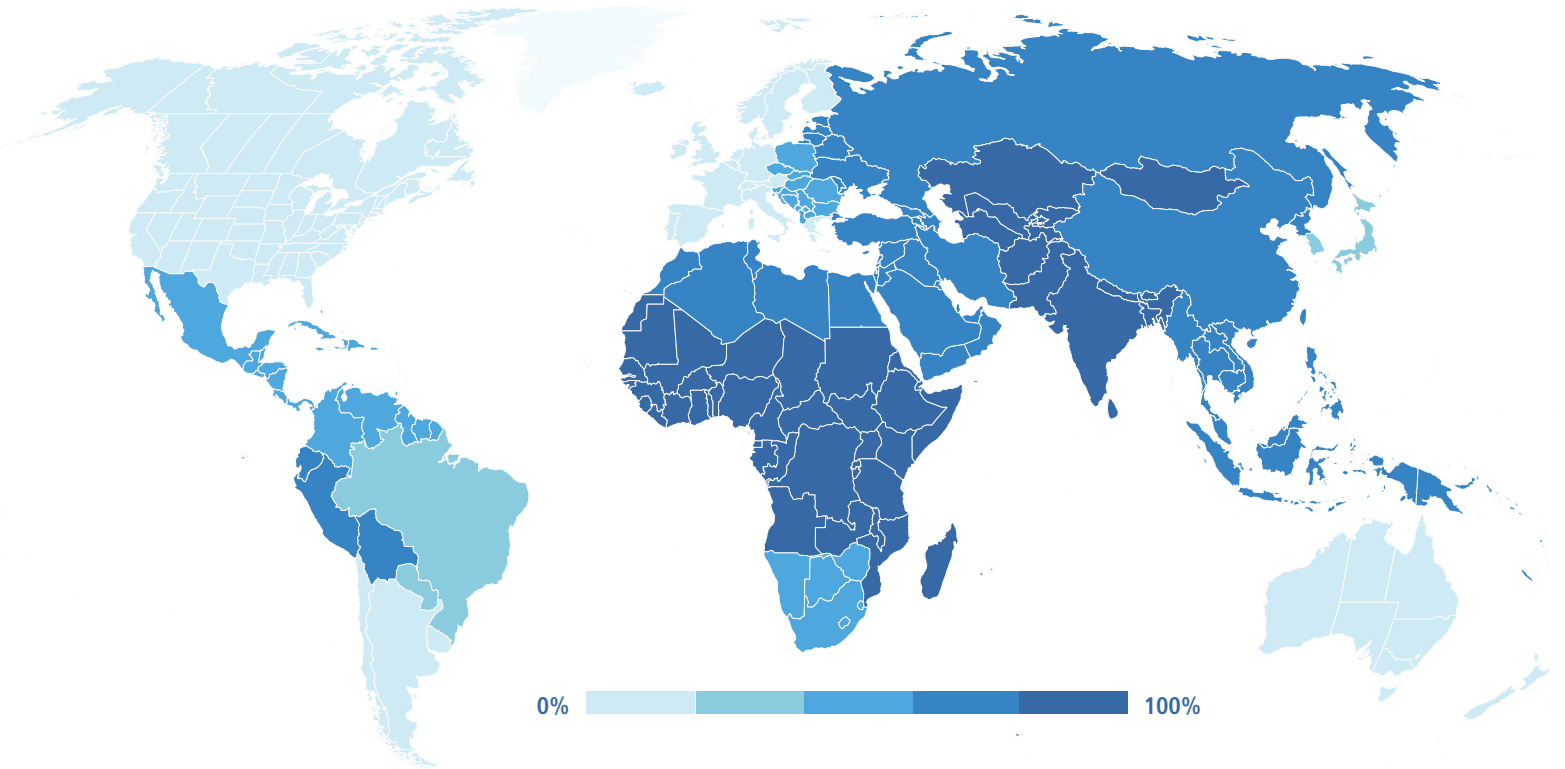
^a50-250 beds; often only one general practice physician or non-physician practitioner

^b200-800 beds; clinical differentiation with 5-10 specialties

^c300-1500 beds; highly specialized with differentiated staff and technical equipment; may include teaching activities

Proportion of Population Without Access to Safe, Affordable Surgery and Anesthesia¹²

(Access to pediatric cardiac surgery is more scarce)



Reliable access to quality care for children with heart disease starts with a primary health care team, including community health workers and midwives.

All providers should be well trained in recognizing the symptoms of heart disease and able to make a referral for follow-up assessment. To achieve this, universal screening and referral guidelines must be developed and adapted to low-resource settings. Likewise, surveillance systems should capture screening data so that the true scope of the problem can be understood and considered in health priority decision making.

Once a cardiovascular problem is suspected, children should be seen by a trained pediatric cardiologist to confirm diagnosis and develop a treatment plan. Herein lies another obstacle. Availability of pediatric cardiologists and surgical centers with the capacity to treat children with heart disease is almost nonexistent in developing countries.

Only 7 percent of the population in developing countries has access to congenital heart disease surgery¹⁶, leaving backlogs of millions of children awaiting life-saving surgery⁵.

Investment in pediatric cardiac care is a long-term investment, synonymous with supporting stronger health systems at large. A cardiac care center cannot operate in isolation. The infrastructure necessary to support children with heart disease—integrated referral systems, supply chain logistics, technical expertise in anesthesiology and infection control, team-based case management—adds resilience to the entire health system. Many organizations and governments are supporting health systems strengthening as a core value for delivering improved outcomes. Including the needs of children with heart disease within these priorities will produce vital outcomes for families, communities and health systems.

Affordability of Care

Congenital heart disease is an expensive disease—for families, for health systems and for communities. Most families do not save for heart surgery for their children; no parent plans for their child to have heart disease. Children who survive untreated heart disease live with a disability that prevents them from playing and learning alongside their peers. As adults they are often limited in their ability to work and contribute to the economic growth of the community, instead relying on social security nets where they are in place, or living in poverty where they are not.

Each year, congenital heart disease is responsible for an estimated 21 million DALYs (disability-adjusted life years)⁵. More than half of these DALYs and 66 percent of deaths are preventable with timely surgical correction. Yet the lack of infrastructure that would support access to care has kept the burden of congenital heart disease high over recent decades. In comparison, childhood diseases with similar burden (e.g., childhood cluster diseases) have seen a 70 percent reduction in DALYs since the turn of the millennium¹⁷.

“By 2030, no one should fall into poverty because of out-of-pocket health care expenses.”¹⁸ We must not cheer World Bank statements like this and then exempt conditions that require subspecialty surgical care. Health care expenses are considered catastrophic when they represent more than 40 percent of a household’s income after basic needs are met, and are a major reason why people delay seeking care. The direct cost of care is further exacerbated by the cost of travel to distant facilities and lost wages from time away from work to

care for sick children. The cost of caring for a child with heart disease can be irrevocably impoverishing for families living without the financial protection of universal health coverage or other health insurance and financing schemes.

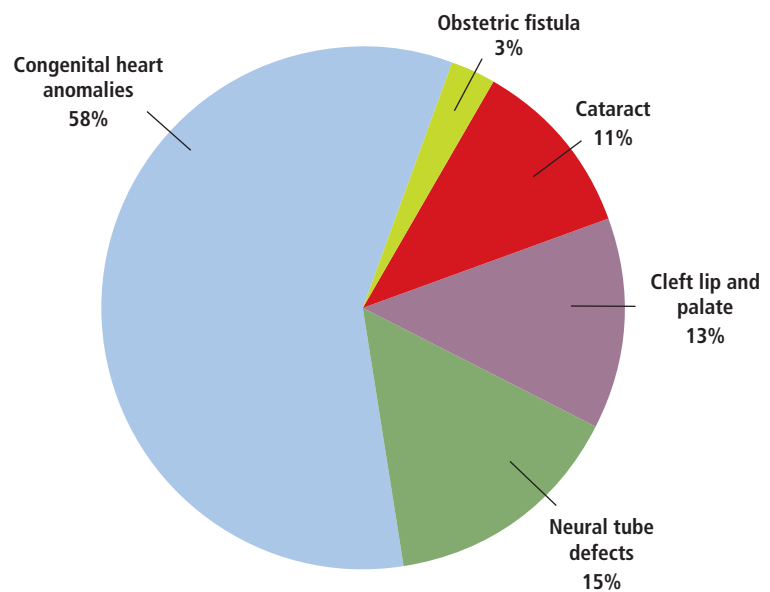
It is unrealistic for a family earning only a few dollars a day to bear the burden of financing the cost of complex medical treatment. Neither is it acceptable for them to watch their child die. Creative financing solutions and political commitments have been made, despite detractors, to meet the tremendous need of once neglected childhood diseases, such as pediatric HIV/AIDS. Children who decades ago would have had little chance of survival are now living to adulthood.

Caring for children with heart disease is expensive, but its cost is not unparalleled nor should it be a

disqualifier for investing in treatment capacity. In countries where health systems priorities include the needs of children with heart disease, surgical costs have been reported to average US \$2,500 - \$5,000¹⁹. This is within the cost range of providing long-term anti-retroviral treatment to children born HIV positive, (US \$4,817 per patient over 19.3 years)²⁰. Without treatment, neither child is likely to survive into adulthood.

It is not a matter of choosing *which* disease a child should die from, but rather of finding innovative funding and sustainable solutions to provide high-quality treatment for all children in need.

Burden of Disease That Could Be Averted by Scaling Up Selected Subspecialty Surgical Care in Low- and Middle-Income Countries⁵



“I get to go to school” — Ai Vy’s Story



Ai Vy is a typical six-year-old girl living in rural Vietnam. She has long, pigtail braids. Her favorite toy is a special doll. She loves school.

Two years ago, however, dreams for success in school seemed far away. She was diagnosed with congenital heart disease when a special screening campaign, organized by cardiologists from the regional hospital, came to her village. The immediate concern for her parents—who support their small family on less than US \$2 per day—was how to manage the care their daughter suddenly and desperately needed.

Ai Vy’s parents borrowed money from family and friends to help cover the costs of surgery and travel to Kien Giang General Hospital, a new Children’s HeartLink partner hospital. They made the two-hour journey from their home to Rach Gia City by motorbike. They couldn’t afford the lost wages that would occur with an extended stay while their only child was recovering in hospital, so Ai Vy’s grandmother volunteered to help with her care.

Before leaving for the hospital, Ai Vy told a young friend, “I am going to go get my heart fixed, and when I come back home I get to go to school.” Indeed she did, and is now a thriving primary school student.

Ai Vy’s case is remarkable, both for her outstanding care and the fact that she was fortunate to receive treatment at all. She is an exception amongst her peer group of children with heart disease. Most children in Vietnam are not screened for heart disease, nor are they in the rest of the developing world. And like most countries, few cardiac centers exist in Vietnam to serve the millions in need.

Kien Giang General Hospital became a Children’s HeartLink partner in 2015, with the goals of strengthening surgical capacity and serving as a regional referral and training center for pediatric cardiology and primary care. In a region that is home to 45 million people, it is the only hospital south of Ho Chi Minh City that can provide pediatric cardiac surgery. Children’s HeartLink’s other partner site in Vietnam, Nhi Dong I in Ho Chi Minh City is the regional training partner for Kien Giang. As the cardiac program at Kien Giang General Hospital advances, their local team will provide high-quality cardiac care for more children like Ai Vy.

Quality of Care

Access to care is irrelevant if the quality of the care received is poor. Quality begins with well-trained personnel, at all levels, who are committed to team-based practice. It requires the availability of necessary and safe equipment and disposables; adherence to infection control and safe surgical procedures; and the ability to monitor clinical outcomes for ongoing quality improvement.

After training, equipment and protocols are met, quality of care is highly dependent on skill. Patient volume allows the surgical team to hone their skills and gain the confidence needed for success in increasingly complex cases. What is often seen, however, is the arrival of international medical volunteer teams to provide short-term care for local patients. While this serves an acute need, it is important that such charitable acts are accompanied by local empowerment and training. Otherwise the arrival and departure of experts from wealthy countries, however well-intended, can serve to erode trust and investment in local capacity¹².

A more sustainable solution is demonstrated by The International Quality Improvement Collaborative²¹, which was initiated to decrease mortality and major complications after congenital heart surgery in the developing world. Participant hospitals achieved significant improvements in mortality and infection rates by focusing on learning experiences in three areas: safer perioperative practice; reduction of surgical site infection and bacterial sepsis; and team-based practice and nurse empowerment²². This shows that investment in local capacity can lead to high-quality, sustainable results.



Conclusion

Congenital anomalies are the fifth leading cause of child mortality¹⁴, with heart disease responsible for the majority of cases of infant illness and death due to birth defect²³. The true incidence of infant deaths due to congenital heart disease is likely to be higher, but will not be known until universal screening and surveillance protocols are developed and global surveillance is adopted.

If the global health community is serious about achieving the Sustainable Development Goal target of “end[ing] preventable deaths of newborns and children under 5 years of age”⁶, it must stop treating advanced cardiac care and surgery as a luxury treatment afforded to the few. Treating children with heart disease can be cost-effective when integrated into health systems strengthening efforts and included within social protection platforms.

Children with congenital heart disease are already born with barriers to health—they should not also face barriers to care.

If the global health community is serious about achieving the Sustainable Development Goal target of “end[ing] preventable deaths of newborns and children under 5 years of age,” it must stop treating advanced cardiac care and surgery as a luxury treatment afforded to the few.

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Series Synopsis

Children's HeartLink is issuing a series of discussion briefs over a 2-year period to engage audiences and bring attention to congenital and rheumatic heart disease within the context of the global health agenda.

Our **first brief**, issued in April 2015, presented the latest available data on the incidence of congenital heart disease and highlighted how frequently the needs of children with heart disease are overlooked.

This, our **second brief**, speaks to how omitting the needs of children with heart disease from discussions about the global health agenda, primary health care and essential surgery maintains the barriers that children with heart disease face when seeking care.

Our **third brief** will discuss the need for sustained investment in health systems, exemplified by Children's HeartLink's success of partnering with local hospitals to meet their population's pediatric cardiac needs within their own health system, with local control and local resources.

Finally, in our **fourth brief** we will present a call to action within the global pediatric care agenda that melds with the broader global health agenda. We will discuss unique opportunities for engagement by governments, health systems, international organizations, donors and civil society.

Children's HeartLink

Children's HeartLink is a Minnesota, USA-based nonprofit humanitarian organization currently working in Brazil, China, India, Malaysia, Ukraine and Vietnam. We partner with local institutions to strengthen health systems in order to develop pediatric cardiac centers of excellence. Evolving from a direct care to a train-the-trainer model, over 5,000 medical professionals are now more equipped to care for children with heart disease. Each year over 80,000 children are served locally through Children's HeartLink partner sites.

www.childrensheartlink.org



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1. A Case for the Invisible Child

(released Spring 2015)

2. Finding the Invisible Child

(released Fall 2015)

3. Treating the Invisible Child

(to be released Spring 2016)

4. A Voice for the Invisible Child

(to be released Fall 2016)

