



Adult Congenital Cardiac Care: A Summary of the Adult Congenital Heart Association Clinic Directory

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Abstract

Background: The Adult Congenital Heart Association (ACHA) is dedicated to supporting patients with congenital heart disease. To guide patients to qualified providers and programs, it maintains a publicly accessible directory of dedicated adult congenital cardiac programs. We analyzed the directory in 2006 and 2015, aiming to evaluate the growth of the directory as a whole and to evaluate the growth of individual programs within the directory. We also hope this raises awareness of the growing opportunities that exist in adult congenital cardiology and cardiac surgery. **Methods:** Data in the directory are self-reported. Only data from US programs were collected and analyzed. **Results:** By the end of 2015, compared to 2006, there were more programs reporting to the directory in more states (107 programs across 42 states vs 57 programs across 33 states), with higher overall clinical volume (591 vs 164 half-day clinics per week, 96,611 vs 34,446 patient visits). On average, each program was busier (5 vs 2 half-day clinics per week per program). Over the time period, the number of reported annual operations performed nearly doubled (4,346 operations by 210 surgeons vs 2,461 operations by 125 surgeons). Access to ancillary services including specific clinical diagnostic and therapeutic services also expanded. **Conclusion:** Between 2006 and 2015, the clinical directory and the individual programs have grown. Current directory data may provide benchmarks for staffing and services for newly emerging and existing programs. Verifying the accuracy of the information and inclusion of all programs will be important in the future.

Keywords

adult congenital heart disease, cardiology, congenital heart surgery, database (all types)

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Introduction

In developed countries, remarkable improvement in survival of patients with congenital heart disease has occurred over the past several decades. It is now estimated that 85% to 90% of patients will survive into adult life, and as of 2000, there are more adults with congenital heart disease than children.¹⁻³ Unfortunately, the infrastructure to care for patients with congenital cardiac disease that is present in most pediatric cardiac centers is lacking within the adult cardiac health-care system.

Both the 32nd Bethesda Conference report in 2001 and the American College of Cardiology (ACC)/American Heart Association (AHA) 2008 Guidelines for the Management of Adults With Congenital Heart Disease provide recommendations for delivery of care to these patients.^{4,5} Among these recommendations, health care for adult congenital heart disease (ACHD) patients should be coordinated by regional ACHD centers of excellence that would serve as a resource for the surrounding medical community, affected individuals, and their families.⁵ In addition, recent studies have also shown that referral to

ACHD care centers is independently associated with a significant mortality reduction, supporting a model of specialized care for all ACHD patients.⁶

The Adult Congenital Heart Association (ACHA) has created an online clinic directory of ACHD centers that provide care for adults with congenital heart disease.⁷ In 2010, we detailed the characteristics of the programs that contributed to the directory.⁸ With the present study, we aim to evaluate the growth of the directory as a whole and the growth of individual programs within the directory.

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Abbreviations and Acronyms

ABTS	American Board of Thoracic Surgery
ACC	American College of Cardiology
ACGME	Accreditation Council of Graduate Medical Education
AHA	American Heart Association
ACHA	Adult Congenital Heart Association
ACHD	adult congenital heart disease
CT	computed tomography
MRI	magnetic resonance imaging

Although reliant on center self-identification and self-reporting, this may provide insight into the current care system, provide benchmarks for staffing and services for newly emerging and existing programs, and raise awareness of the growing opportunities that exist in adult congenital cardiology and cardiac surgery.

Methods

The ACHA is dedicated to supporting patients with congenital heart disease and maintains a directory of dedicated adult congenital cardiac programs.⁷ The directory incorporates all self-identified adult congenital cardiac programs. The data are self-reported and publicly available for evaluation and analysis. Only programs within the United States were included in this analysis. Topics of interest included the number and distribution of programs, year of program formalization, program volume and clinical setting, program personnel, and services provided. The number of half-day clinics is defined as a half-day clinic for a single provider. Summary statistics were provided throughout, and comparisons were made between the 2006 and 2015 directories.

Institutional review board approval was waived since the data are publicly available and does not involve protected health information.

Results

Program Number, Distribution, and Longevity

In 2006, there were 57 programs in the clinic directory, which are distributed among 32 states and Washington, DC. As of 2015, five of these programs no longer submit data to the directory. There are currently 107 programs distributed among 41 states and Washington, DC, with a median of 2 programs (range: 1-12) per state. Only nine states do not have a program contributing to the directory (Figure 1).

The current programs in the directory reported becoming formalized between 1974 and 2014. By decade, 2 programs were formalized in the 70s, 6 in the 80s, 20 in the 90s, 50 in the 2000s, and an additional 29 since 2010 (Figure 2). Of the 55 new programs in the directory since 2006, a total of 16 were formalized prior to 2006 but did not start contributing to the directory until after 2006, and 39 were formalized after 2006.

Care Setting and Volumes of the Current Directory

Reported care settings were variable and fell into one of four categories: (1) all ACHD care provided within a facility primarily geared toward caring for adult patients, (2) all ACHD care provided within a facility primarily geared toward caring for pediatric patients, (3) some ACHD care provided within a facility primarily geared toward caring for adult patients and some ACHD care provided within a facility primarily geared toward caring for pediatric patients, and (4) ACHD care provided within a facility that is geared toward caring for both adult and pediatric patients.

Outpatient care was provided within adult facilities only ($n = 14$, 13%), pediatric facilities only ($n = 4$, 4%), or within both adult and pediatric facilities individually ($n = 89$, 83%). Among all programs, a total of 96,611 patient visits/year were reported during 591 half-day clinics/week. The median number of half-day clinics/week/program was five (range: 0.5-18), and the median number of clinic visits/year/program was 604 (range: 30-3,500; Table 1)

Inpatient care was provided within adult facilities only ($n = 14$, 13%), pediatric facilities only ($n = 10$, 9%), both adult and pediatric facilities individually ($n = 48$, 45%), and combined adult/pediatric facilities ($n = 35$, 33%). Programs reported a total of 4,346 adult congenital operations per year, with a median of 30 (range: 0-400) per program; 15 programs did not have surgical services (Table 1).

Personnel

All programs reported having a designated program director. The program director had a median of 14 (range: 1-36) years of adult congenital cardiac experience and devoted 40% (range: 5%-100%) of time to the program. Program director certifications included internal medicine cardiology ($n = 47$), pediatric cardiology ($n = 50$), both ($n = 9$), and cardiothoracic surgery ($n = 1$).

Forty-four programs reported having a designated program codirector. The program codirector had a median of 15 (range: 2-51) years of adult congenital cardiac experience and devoted 30% (range: 2%-100%) of time to the program. Program codirector certifications include internal medicine cardiology ($n = 14$), pediatric cardiology ($n = 24$), both ($n = 2$), and cardiothoracic surgery ($n = 4$).

Across all programs, there were 397 additional cardiologists, with a median of 4 (range: 0-14) per program, and 58 advanced practice providers, with a median of 0 (range: 0-5) per program. There are 210 surgeons performing adult congenital cardiac surgery, with a median of 2 (range: 0-6) per program (Table 1). For the 4,346 adult congenital operations, each surgeon performed an average of 21.7 operations per year.

Resources and Services Provided

As of 2015, a total of 107 programs reported having staff cardiologists, 51 programs reported having advanced

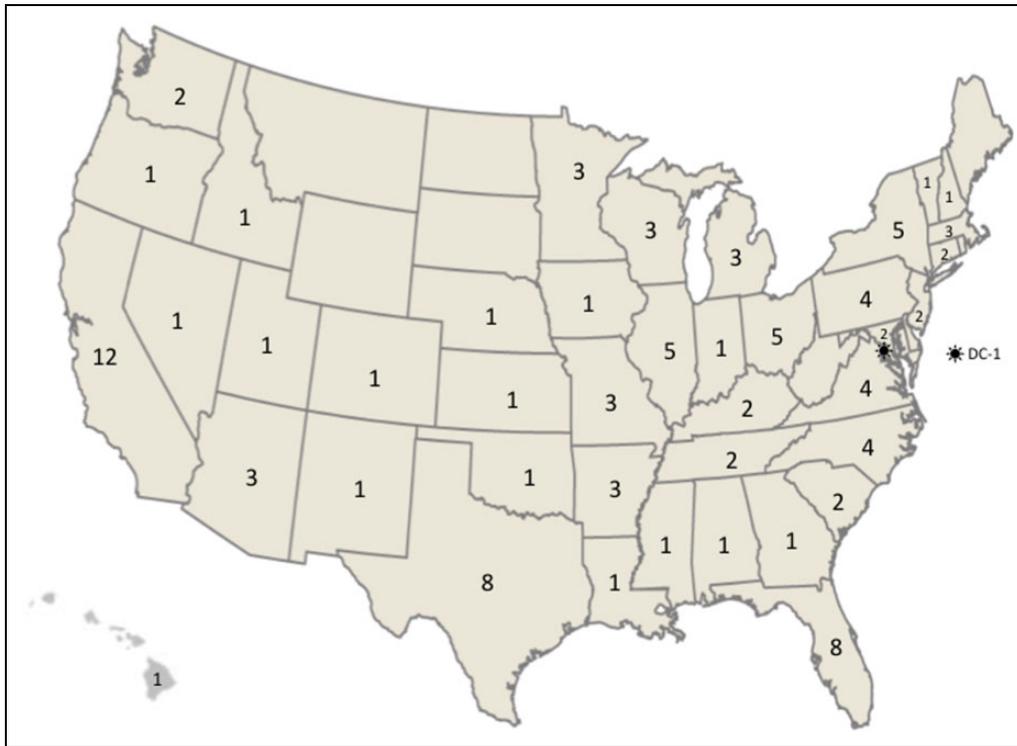


Figure 1. The ACHD program distribution. National distribution of programs in the clinic directory, shown by the number of programs in each state. ACHD indicates adult congenital heart disease.

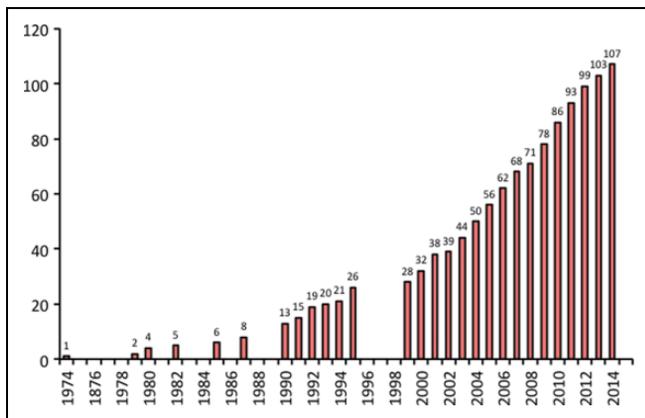


Figure 2. Cumulative programs formalized by year. Cumulative number of programs formalized each year beginning in 1974 to reach to the current clinic directory total of 107.

practice providers, and 95 programs reported having cardiac surgeons as part of the adult congenital team. For every 1,000 clinic visits, the median number of staff cardiologists in each program was 7.8 (1.5-109.6), the median number of advanced practice providers in each program was 1 (0.3-13.7), and the median number of cardiac surgeons was 2.7 (0.5-41.1; Table 1).

Diagnostic and therapeutic services, such as echocardiography, diagnostic and interventional cardiac catheterization, diagnostic and interventional electrophysiology, cardiac computed tomography (CT), and cardiac magnetic resonance

Table 1. Summary of Care Settings, Volumes, and Personnel.

n = 107	Median (range)	n (%)
Outpatient		
Setting		
Adult facility		14 (13%)
Pediatric facility		4 (4%)
Both adult and pediatric facilities		89 (83%)
Patient visits/year	604 (30-3,500)	
Number of half-day clinics	5 (0.5-18)	
Inpatient		
Setting		
Adult facility		14 (13%)
Pediatric facility		10 (9%)
Combined facility		35 (33%)
Both adult and pediatric facilities		48 (45%)
Surgical volume age >18	30 (0-400)	
Personnel per program		
Staff cardiologists (397)	4 (0-14)	
Nurse practitioners (58)	0 (0-5)	
Surgeons performing ACHD surgery (210)	2 (0-6)	
Personnel per 1,000 patient visits		
Staff cardiologists	7.8 (1.5-109.6)	
Nurse practitioners	1 (0.3-13.7)	
Surgeons performing ACHD surgery	2.7 (0.5-41.1)	

Abbreviation: ACHD, adult congenital heart disease.

imaging (MRI), were reportedly available in 96% to 100% of programs. Subspecialty and ancillary services, such as obstetrics, pulmonary hypertension, contraceptive counseling,

Table 2. Program Services.

n = 107	n (%)
Diagnostics/therapeutics	
Echocardiography	107 (100%)
Diagnostic cardiac catheterization	103 (96%)
Interventional cardiac catheterization	101 (94%)
Diagnostic electrophysiology	106 (99%)
Interventional electrophysiology	103 (96%)
Cardiac CT	104 (97%)
Cardiac MRI	105 (98%)
Subspecialty/ancillary services	
Obstetrics	103 (96%)
Pulmonary hypertension	101 (94%)
Contraceptive counseling	105 (98%)
Genetic counseling	101 (94%)
Psychiatry	82 (77%)
Rehabilitation	95 (89%)
Financial counseling	96 (90%)
Social work	88 (82%)
Teaching	
Dedicated ACHD fellowship	21 (20%)
Research	
Publications within five years	86 (80%)

Abbreviations: ACHD, adult congenital heart disease; CT, computed tomography; MRI, magnetic resonance imaging.

genetic counseling, psychiatry, rehabilitation, financial counseling, and social work, were reportedly available in 77% to 96% of programs (Table 2).

Comparison Between the 2006 and 2015 Directories

By the end of 2015, compared to 2006, there were more programs reporting to the directory in more states (107 programs across 42 states vs 57 programs across 33 states), with higher overall reported clinical volume (591 vs 164 half-day clinics per week, 96,611 vs 34,446 patient visits). On average, each program was busier (5 vs 2 half-day clinics per week per program, 604 vs 500 visits per program per year). Over the time period, the reported number of annual operations performed nearly doubled (4,346 operations by 210 surgeons vs 2461 operations by 125 surgeons; Table 3).

Growth of the Original Programs

Fifty-two of the participating programs were present in both the 2006 and 2015 clinic directories. Among these programs only, there were increases in the total number of half-day clinics per week (374 vs 158), the number of yearly clinic visits (66,267 vs 34,015), and the number of staff cardiologists (212 vs 139). However, from a surgical standpoint, these programs showed minimal reported growth in the number of operations performed per year (2,469 vs 2,440) and the number of surgeons performing these operations (124 vs 121; Table 4).

Discussion

Clinic Directory Structure

The ACHD clinic directory offers program information among ACHD clinics that currently participate in the ACHA clinic survey project.⁷ Programs can be added to the directory by filling out a survey. All data in the ACHD clinic directory are self-reported and are not independently verified. These clinics vary widely in size, training, and services offered. There are likely centers providing ACHD medical and surgical care that are not included in the directory, so it is unclear as to how much additional care these centers are providing and what the reasons may be for nonsubmission.

In 2016, the ACHA will begin making program site visits, with the intention of verifying the information in the clinic directory. Of note, the ACHA does not endorse or recommend any particular ACHD clinic.

Clinic Directory and Individual Program Growth

As shown, the clinic directory has grown from the 57 programs in 2006 to 107 programs in 2015 (55 new programs with 5 programs withdrawing). Of the 55 new programs, 16 reported being formalized prior to 2006. Although these programs represent increased penetrance into the clinic directory, they do not necessarily represent increased infrastructure in the ACHD care system. On the other hand, 39 programs reported being formalized after 2006. These programs represent both increased penetrance into the directory and increased infrastructure.

Comparing the 52 programs present in both the 2006 and 2015 clinic directories, the total number of half-day clinics per week increased, the number of yearly clinic visits increased, and the number of staff cardiologists increased. The number of operations and the number of surgeons increased as well, albeit more modestly.

Overall, this growth demonstrated an increase in program access and availability over time, with more programs in more states, and showed an increase in per-program volume for ACHD specialized clinics.

Personnel Qualification

The clinical directory reported the following information about program personnel: number, training history, years of experience, and time devoted to the program. For the program directors, the reported years of ACHD experience was quite variable, as was their time devoted to ACHD practice. A similar variability applied to the program codirector, and nothing is known about the training, experience, and devotion of the additional 397 staff cardiologists and 210 cardiac surgeons.

For cardiologists, in 2012, the American Board of Internal Medical Subspecialties approved ACHD as a subspecialty of both internal medicine cardiology and pediatric cardiology.⁹ Currently, practicing cardiologists can achieve certification by documentation of appropriate experience

Table 3. Clinic Directory Growth 2006 to 2015.

	2006 (n = 57)		2016 (n = 107)	
	n (%)	Median (range)	n (%)	Median (range)
Clinics				
Total visits/year	34,446		96,611	
Total visits/year/program		500 (57-2,880)		604 (30-3,500)
Total ½-day clinics/week	164		591	
Total ½-day clinics/week/program		2 (0.5-10)		5 (0.5-18)
Staff cardiologists				
Total number nationally	150		397	
Number/program		2 (0-12)		4 (0-14)
Surgeons/operations				
Total number operations nationally	2,461		4,346	
Number of operations/program		40 (0-230)		30 (0-400)
Total number of surgeons nationally	125		210	
Number of surgeons/program		2 (0-5)		2 (0-6)
Mean ACHD operations/year/surgeon	19.8		20.7	

Abbreviation: ACHD, adult congenital heart disease.

Table 4. Individual Program Growth 2006 to 2015.

	2006 (n = 52)		2016 (n = 52)	
	n (%)	Median (range)	n (%)	Median (range)
Clinics				
Total visits/year	34,015		66,267	
Total visits/year/program		500 (57-2,880)		1,088 (200-3,400)
Total ½-day clinics/week	158		374	
Total ½-day clinics/week/program		2 (0.5-10)		8 (1-18)
Staff cardiologists				
Total number nationally	139		212	
Number/program		2 (0-12)		4 (0-10)
Surgeons/operations				
Total number operations nationally	2,440		2,469	
Number of operations/program		40 (0-230)		40 (0-170)
Total number of surgeons nationally	121		124	
Number of surgeons/program		2 (0-5)		2.5 (0-6)
Mean ACHD operations/year/surgeon	20.2		19.9	

Abbreviation: ACHD, adult congenital heart disease.

and passing a written board examination. After 2019, subspecialty certification will require the completion of an Accreditation Council of Graduate Medical Education (ACGME)-accredited two-year fellowship in ACHD following adult or pediatric cardiology training.⁹

For surgeons, in 2007, the American Board of Thoracic Surgery approved congenital cardiac surgery as a subspecialty of thoracic surgery, encompassing the practice of surgery to treat congenital heart defects in neonates, children, and adults.¹⁰ Since 2014, subspecialty certification requires the successful completion of an ACGME-accredited one-year residency as well as passing a qualifying written examination and a certifying oral examination.¹⁰

Although many of the personnel providing ACHD care may have accumulated a great deal of knowledge from years of exposure to these patients, these specific medical and surgical

training pathways now exist. It is unclear at this time whether the cardiologists and the cardiac surgeons in the directory are board certified in adult congenital cardiology or congenital cardiac surgery, respectively, and this may be an opportunity for the future directory updates.

Services Provided

These patients can be extraordinarily complex, and successful treatment requires a multidisciplinary collaborative approach. Per the 2008 guidelines, important components of the multidisciplinary team include high-risk obstetrics, pulmonary hypertension, heart failure/transplant, genetics, neurology, nephrology, cardiac pathology, rehabilitation services, social services, vocational services, and financial counselors.^{5,11} Of those assessed, the subspecialty/ancillary services were

reported present in 77% to 96% of programs, depending on the specific service.

Certain diagnostic and therapeutic services are also important for the care of these patients. Per the 2008 guidelines, these include echocardiography (including transesophageal echocardiography [TEE] and intraoperative TEE), diagnostic and interventional cardiac catheterization, electrophysiology/pacing/automatic implanted cardioverter defibrillator (AICD), exercise testing (echocardiographic, radionuclide, cardiopulmonary, metabolic), and advanced cardiac imaging (cardiac MRI, CT, nuclear medicine).^{5,11} It is also suggested that information technology services should be available that allow for data collection, database support, and quality assessment.^{5,11} Of those assessed, the services were reported present in 94% to 100% of the programs, depending on the specific service.

Benchmarks

Despite its growth as indicated by the clinic directory, it remains unclear as to whether our current system is meeting the demands of adult congenital cardiac patients. The level of staffing displayed in the current directory and the high frequency at which various services are provided may provide important benchmarks for newly emerging and existing adult congenital cardiac programs. Clinicians may benefit from having this data when advocating for additional program, personnel, and service-related resources to care for this ever growing population.

Limitations

As mentioned throughout, there are numerous limitations to the analysis. Program information in the directory is self-reported and nonvalidated. The directory does not include all programs that provide ACHD care, and it is unclear if program staff members are ACHD board certified. Some of the growth in the directory between 2006 and 2015 represents penetrance into the directory, particularly for those programs formalized prior to 2006, rather than an increase in the infrastructure of the ACHD care system. Hopefully with time and program verification, some of these issues may be minimized or eliminated.

Conclusions

The ACHA ACHD clinic directory characterizes the centers and personnel that care for adult congenital cardiac patients. Between 2006 and 2015, the clinical directory has nearly doubled, and there has been an increase in reported clinic days, patient visits, and services provided. Current directory data may provide benchmarks for staffing and services, may provide validation to clinicians advocating for program resources, and may raise awareness to the growing opportunities that exist in adult congenital cardiology and cardiac surgery. Verifying the accuracy of the information submitted and the inclusion of all adult congenital cardiac programs in the directory may be important for the future, the ultimate goal being to improve access and care for ACHD patients across the nation.

Authors' Note

Brian Kogon was involved with study design, data collection/analysis, statistics, manuscript preparation and critical review. Kati Miller contributed to data collection, manuscript preparation, and critical review. Paula Miller contributed to creation and maintenance of the clinic directory, manuscript preparation, and critical review. Glenn Tringali was involved with creation and maintenance of the clinic directory, manuscript preparation, and critical review. Joshua Rosenblum was involved with data collection, manuscript preparation, and critical review.

Declaration of Conflicting Interests

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