Access and Delivery of Adult Congenital Heart Disease Care in the United States: Quality-Driven Team-Based Care

Susan M. Fernandes, LPD, PA-C[a,*], Ariane Marelli, MD, MPH[b], Danielle M. Hile, BS[c], Curt J. Daniels, MD[d]

KEYWORDS

• Adult congenital heart disease • Access and delivery of care • Care models

KEY POINTS

- The adult congenital heart disease (ACHD) population has surpassed current abilities to provide high-quality care.
- To improve access and delivery of high-quality care requires developing and growing ACHD centers in areas of greatest need.
- The ACHD centers of excellence (accredited centers) are grounded in a team-based approach to deliver care.

As described by Marelli and colleagues,[1] the number of adult congenital heart disease (ACHD) patients are growing at a rate faster than those with pediatric congenial heart disease (CHD). These ACHD patients are highly complex, suffer from multi organ disease and require great cardiovascular (CV) care and ACHD expertise. The ability to provide high-quality ACHD care in many areas of the United States is challenging due to a limited number of providers and numerous access to care issues. ACHD as a subspecialty in the United States produced fewer than 100 ACHD cardiologists over 2 decades and fell behind the rising ACHD patient population. More recently, with board certification and certified training pathways, the quality of ACHD care is improving, but access to this care remains well behind patient demand. Meeting the demands for access to high-quality ACHD care will require not only a focus on increasing the numbers of ACHD cardiologists but also expanding the use of team-based care (TBC). This article defines ACHD TBC, discusses the various team specialists and their responsibilities, demonstrates current gaps in care, and describes areas of need for the future.

TEAM APPROACH TO CARE IN ADULT CONGENITAL HEART DISEASE

The care of adults with CHD, in particular those with more complex disease, requires a capable team that can work together to provide high-quality patient-centered care. TBC, the "provision of health services to individuals, families, and

[a] Adult Congenital Heart Program Stanford, Stanford Health Care, Lucile Packard Children's Hospital Stanford, Stanford University, School of Medicine, 150 Governor's Lane, Stanford, CA 94305, USA; [b] McGill Adult Unit for Congenital Heart Disease Excellence (MAUDE Unit), Division of Cardiology, McGill University, RVH/Glen Site, D055108, 1001 Decarie Boulevard, Montreal, Quebec H4A3J1, Canada; [c] Adult Congenital Heart Association, 280 North Providence Road, Suite 6, Media, PA 19063, USA; [d] Columbus Ohio Adult Congenital Heart Disease Program, Department of Internal Medicine and Pediatrics, The Ohio State University, Nationwide Children's Hospital, 451 West 10th Avenue, Columbus, OH 43210, USA
* Corresponding author.
E-mail address: sfernandes@stanford.edu

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communities by at least two health providers who work collaboratively with patients and their caregivers to accomplish shared goals and achieve coordinated, high-quality care," has been shown to improve patient care and efficiency while decreasing costs.[2] In CV medicine, TBC has been associated with improvements in medication compliance, care outcomes, and quality of life and with decreased health care costs.[3,4]

TBC has not been studied specifically in the ACHD population but has been accepted as best practice. One of the main goals of the International Society for Adult Congenital Heart Disease is "to promote a holistic team-based approach to the care of the adult with congenital heart disease that is, comprehensive, patient-centered, and interdisciplinary."[5] The Adult Congenital Heart Association (ACHA) ACHD Accreditation Program (www.achaheart.org) also highlights the importance of the TBC, requiring more than 10 different types of providers to meet criteria for program accreditation.

The CHD patient experience with the health system spans pediatric and adult hospitals and takes place in ambulatory, inpatient, and critical care units; operating rooms; advanced imaging suites; and cardiac catheterization, electrophysiology, and exercise testing laboratories. In these settings, they interact with a wide range of providers, including but not limited to surgeons, anesthesiologists, physician assistants (PAs), nurse practitioners (NPs), nurses, pharmacists, technicians, a wide range of congenital and internal medicine cardiologists, and numerous internal medicine subspecialty providers. With the complexity of providing ACHD care, it would be easy for patients to interact with these environments and providers in isolation, but high-performing programs put the ACHD patient in the center of care, with the team members communicating with the patient and each other. Anchoring the model of TBC in ACHD is the core ACHD team (**Table 1**), which typically includes ACHD cardiologists, NPs or PAs, nurses, psychologists, social workers, and administrative support. This front-line team provides patients 24/7 access, coordinates care, and ensures that all physical and emotional needs are addressed. The ACHD cardiologist typically is the leader of this team, providing oversight for the medical care provided by team members, guiding members to function at the top of their skill set, and providing feedback and space for ongoing professional development. Each member of the team, however, should be seen as a potential leader. When a patient care scenario arises for which another member of the team has the best-suited training and expertise to guide the team, that member should be encouraged to step forward into that role. A well-functioning team has shared purpose or goals, effective leadership, communication, cohesion, and mutual respect. They are open to the professional contributions of each team member while recognizing and respecting their unique skills.[6]

ADULT CONGENITAL HEART DISEASE ADMINISTRATIVE SUPPORT

Each member of the ACHD team plays an integral role. Although administrative positions are not required for ACHA ACHD program accreditation, 89% of programs reported having at least 1 person dedicated to an administrative role. This administrative support person often is the first person an ACHD patient interacts with and can set the tone for future interactions with the team. How programs utilize administrative support is highly variable, although frequently this person is in charge of complex scheduling, data gathering, processing paperwork for insurance authorizations and disability approval, and calendar tracking of patient admissions, surgeries, and other procedures. They can guide other schedulers (such as surgical schedulers) in balancing activities for the ACHD team so that adequate resources are available for ACHD consultation. In addition, the administrative support person typically manages the team calendar (team meetings, on-call and on-service times, vacations, and so forth), identifies and books meeting rooms, orders office supplies, and provides additional administrative support services as requested. The title of this administrative role within the ACHD team varies from program to program, with administrative coordinator, patient care coordinator, operations specialist, and administrative associate a few of the common titles.

Over the past few years, there has been an increasing number of programs hiring an administrative program director or manager. Currently, 66% of accredited ACHD programs report having someone in this role. Typically, this person has managerial, financial, and business strategy experience. In partnership with the ACHD medical director, this administrative leadership person can manage program performance tracking (volume and finances), provide justification for additional resources, and identify and support opportunities for growth. They can provide leadership for process improvement projects to optimize efficiency and patient satisfaction. Their direct reporting to hospital administration provides an opportunity for the ACHD team to have visibility at the hospital leadership level and a voice at the decision-making table. This is true particularly when the

Table 1
Team-based care in adult congenital heart disease core team roles

Role	
Administrative support • Administrative coordinator • Patient care coordinator • Operations specialist • Administrative associate	• Performs basic and complex scheduling • Manages data • Obtains outside medical records, imaging, and testing results • Manages support data (volume tracking and finances) • Processes paperwork (insurance and disability) • Manages calendar (patient and team) • Acts as liaison to procedural schedulers • Performs general administrative tasks
Administrative leadership • Program manager • Program director	• Provides managerial, financial, and business support for the ACHD program • Provides leadership for program vision and strategy initiatives • Manages data and database • Tracks activities to support justification for additional resources • Processes improvement activities • Acts as liaison to institutional administrative leadership • Provides leadership for program accreditation initiation and compliance
Nurse coordinator	• Coordinates care • Tracks testing and ensures patients follow and timely review of test results • Manages active patient list • Triages phone • Provides clinic support • Provides patient education • Provides counselling • Coordinates ACHD research and scholarly output • Provides ACHD community engagement
Mental health professional • Social worker • Psychologist	• Evaluates, diagnoses, and provides treatment of mental and emotional disorders • Assesses intellectual functioning (psychologist) • Provides psychotherapy and counseling • Connects patients to local resources (social worker) • Provides logistical support, such as transportation and accommodations (social worker) • Processes insurance and disability paperwork (social worker and nurse case manager) • Provides support for completing legal documents, such as advanced directive (social worker) • Coordinates ACHD research and scholarly output • Provides ACHD community engagement
APP • NP • PA	• Assesses, diagnoses, and manages ACHD patients across all health care settings • Orders and interprets CV testing • Provides patient education • Coordinates ACHD research and scholarly output • Provides ACHD community engagement

(*continued on next page*)

Table 1
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Role	
ACHD cardiologist	• Provides leadership for the ACHD team • Assesses, diagnoses, and manages ACHD patients across all health care settings • Performs and interprets invasive and noninvasive cardiovascular testing • Coordinates ACHD research and scholarly output • Provides ACHD community engagement • Provides leadership for program vision and strategy initiatives (medical director) • Provides leadership for activities to improve care quality (medical director)

role is a director-level position. Likely a driving force behind programs adding this type of role is to support initial ACHD program accreditation and to ensure future compliance. Approximately half of those listed in this administrative leadership role, within accredited programs, have administrative backgrounds. The remaining individuals have clinical backgrounds as well, allowing them to carry out the responsibilities, discussed previously, and to provide oversight of the nonphysician members of the ACHD team. This administrative leader benefits programs because they are acutely aware of program needs and the roles of each team member, allowing them to advocate effectively for additional resources as needed. They also can provide data and advocate to keep members from being pulled to other programs or service lines.

NURSE COORDINATOR

In acknowledgment of the vital role that nurses play in the care of the ACHD patients, accreditation requirements mandate that all programs have a full-time dedicated ACHD nurse. In most programs, this role is best described as a nurse coordinator. A 2017 article by Sillman and colleagues,[7] which includes input from nurses representing 10 ACHD programs from 8 countries, provides a comprehensive overview of the essential skills provided by the ACHD nurse coordinator. The nurse coordinator works in tandem with other members of the ACHD team, with the main focus of their activities centered around care coordination, phone triage, patient education, and counseling. There frequently is some overlap between the nurse coordinator and the advanced practice provider (APP) (NP or PA) role in ACHD programs. When nurse coordinators are utilized to their full level of expertise and practice scope, however, that allows an NP or PA to focus on increasing access to care. Given the shortage of ACHD providers, optimization of each member's role is crucial.

The care coordination provided by the nurse coordinator is supported by the administrative team as the nurse coordinates complex assessments that may require multiple specialists and procedures. They place orders for cosignatures, ensure that patients follow through on recommendations, and ensure that testing results are reviewed promptly by the ACHD providers. Typically, the nurse coordinator is responsible for keeping the active patient list and preparing the list for team meetings while providing updates at these team meetings as needed. The nurse coordinator typically spends large portions of the day triaging patient calls, typically filtered by the administrative team so that only clinical calls move to the nursing team. The calls frequently are related to ongoing symptoms, questions about medications, and psychosocial concerns. The ACHD nurse coordinator must have the skills to guide patients regarding these concerns. In the outpatient clinic, the nurse coordinator can take the lead on providing patient education regarding medication management, heart failure, pregnancy and contraception, self-care management and self-advocacy, preprocedural and postprocedural guidance, endocarditis prevention, and prevention and lifestyle choices. The nurse coordinator also plays a key role in ensuring all patients have an advanced directive on file and typically helps lead the patient-centered discussion regarding care goals and end of life care.

MENTAL HEALTH PROFESSIONAL

Psychosocial challenges are common in the ACHD patient population. Depression, anxiety, and posttraumatic stress disorders are seen more

frequently than in the general population.[8–11] Participation in high-risk behaviors also is noted along with challenges regarding relationships, education, and employment attainment, which can have an impact on quality of life for ACHD patients.[12–15] The need for mental health support in ACHD patients is recognized and is a core component of the ACHA ACHD accreditation criteria. A social worker or clinical psychologist plays an integral role in supporting patients through these mental health challenges. The psychologist evaluates and diagnoses mental and emotional disorders and intellectual functioning and provides psychotherapy. Social workers typically provide psychosocial evaluations and counseling; they frequently are able to provide crisis intervention while awaiting an appointment with a psychologist or psychiatrist and can connect the ACHD patient to other local resources and support groups. In some instances, the social worker (or in some programs the ACHD nurse case manager) is involved with supporting activities to obtain disability benefits and insurance access, supporting patients in developing advanced directive plans and providing more logistical support, such as helping to secure financial support for transportation and accommodations to appointments and procedures.

Although there is an overlap in some aspects of training between the mental health professional and the ACHD cardiologist, NP, and PA colleagues, they typically have a greater depth and breadth of training in mental health. Given this, when mental health concerns are the dominating patient issue, the social worker or psychologist should be allowed to step in the ACHD team leadership role to guide the team in how to provide the best care to the patient. When the ACHD provider identifies issues that are having an impact on a patient's emotional well-being, such as a poor prognosis, the mental health professional can play an integral role working with the ACHD team and the patient to ensure a holistic approach to care. This social worker and/or psychologist participating in the care of the ACHD patient also can allow the ACHD providers to focus on CHD issues, ensuring efficiency and effectiveness of patient care while increasing access.

ADVANCED PRACTICE PROVIDER

APPs, such as PAs and NPs, are the fasting growing health care careers in the United States, and the demand for such providers is expected to grow 30% over the next 10 years (U.S. Bureau of Labor Statistics. Occupational Outlook Handbook: Fastest Growing Occupations; https://www.bls.gov/ooh/fastest-growing.htm). Driving this demand in the United States is an increased number of patients entering the health care system, a shortage of physician providers, and a reduction in trainee work hours (https://www.aamc.org/system/files/c/2/31-2019_update_-_the_complexities_of_physician_supply_and_demand_-_projections_from_2017-2032.pdf). Although there are significant training differences between NPs, who train in an advanced nursing model, and PAs, who train in the medical model, their roles within health care frequently are indistinguishable. As a group, under the umbrella term APP, they have proved themselves high-quality providers who deliver excellent care and increase access to care, while decreasing overall health care costs.[16–19] Based on this evidence, academic medical centers across the United States have embraced APPs as a way to increase access to care, with a median utilization of 1 APP to every 5 physicians.[20]

The American College of Cardiology (ACC) 2020 clinical competencies for cardiovascular NPs and PAs outlines the expected medical knowledge and skills for all CV PAs and NPs and the aspiring knowledge and skills for those with a focused practice area, such as ACHD.[21] This document can inform ACHD cardiologists, administrative leaders, and others involved in building ACHD teams in how to optimize the utilization of APPs. The transition from a general CV APP to a highly specialized ACHD APP requires supportive training and mentoring by an ACHD cardiologist and an active pursuit of professional development by the APP. Over time, the ACHD APP can exhibit, often with significant autonomy, the medical knowledge and clinical skills of a highly competent ACHD provider, providing near similar care to a collaborating ACHD cardiologist.

Given the number of patients, the current shortage of ACHD cardiologists is unlikely to be resolved in the near future. The long training pathway to becoming an ACHD cardiologists also is likely to be a barrier to increasing the number of cardiologists wanting to specialize in ACHD. Expanding the reach of the ACHD cardiologist with the training and utilization of APPs is warranted. A study by Green and colleagues[22] showed that the shortage of primary care providers could be effectively eliminated by shifting care to APPs for 23% of patients. A similar approach in ACHD, with shifting the care of less complex cases to the ACHD APP, could be as effective. There may be a temptation, especially in centers with limited resources, to utilize APPs to do work that can be done by a nurse coordinator, case manager, or social worker. Given the shortage of ACHD cardiologists

and that only physicians and APPs can assess, diagnose, manage, and prescribe medications to ACHD patients, APPs must be solely utilized in their advanced practice capacity to increase access to care for ACHD patients.

CARDIOLOGIST

Training for ACHD cardiology was formalized in 2013 with Accreditation Council for Graduate Medical Education (ACGME) approval for a 2-year curriculum after either pediatric or internal medicine cardiology. Prior to formalized training, most cardiologists interested in ACHD completed non-ACGME training, which took the form of either variable time-related training—6 months to 2 years with a mentor or mentors—or completing a full combined internal medicine and pediatric cardiology fellowship over 5 years or 6 years. Over the span of 20 years from 1997 to 2011, only 67 cardiology fellows trained in some capacity at 11 institutions in the United States. The mentorship and nonformalized training provided the early stages of ACHD as a subspecialty in the United States and led to the petition to formalize training through ACGME. This also led to ACHD expertise to submit the petition for ACHD board certification and the development of ACHD clinics and programs around the country. Current ACGME ACHD programs can be found at https://www.acgme.org/Residents-and-Fellows/The-ACGME-for-Residents-and-Fellows.

In 2012, the American Board of Internal Medicine, American Board of Pediatrics, and American Board of Medical Specialties approved the petition for ACHD as a CV subspecialty. Unique and critical to this process was the approval by the American Board of Pediatrics for ACHD as a subspecialty with a pathway through pediatric cardiology. In 2020, there are 455 board-certified ACHD cardiologists in the United States. The distribution of ACHD cardiologists in the United States shows geographic diversity but leaves many areas of the country underrepresented (Fig. 1).

Ideally, each patient should have access to a board-certified ACHD cardiologist, but there are insufficient numbers to provide care to the more than 1.5 million ACHD patients in the United States. For the foreseeable future, there will be insufficient number of ACHD cardiologists to match the size and trajectory of patients in the United States. Expanding the reach of the ACHD cardiologist through TBC is warranted.

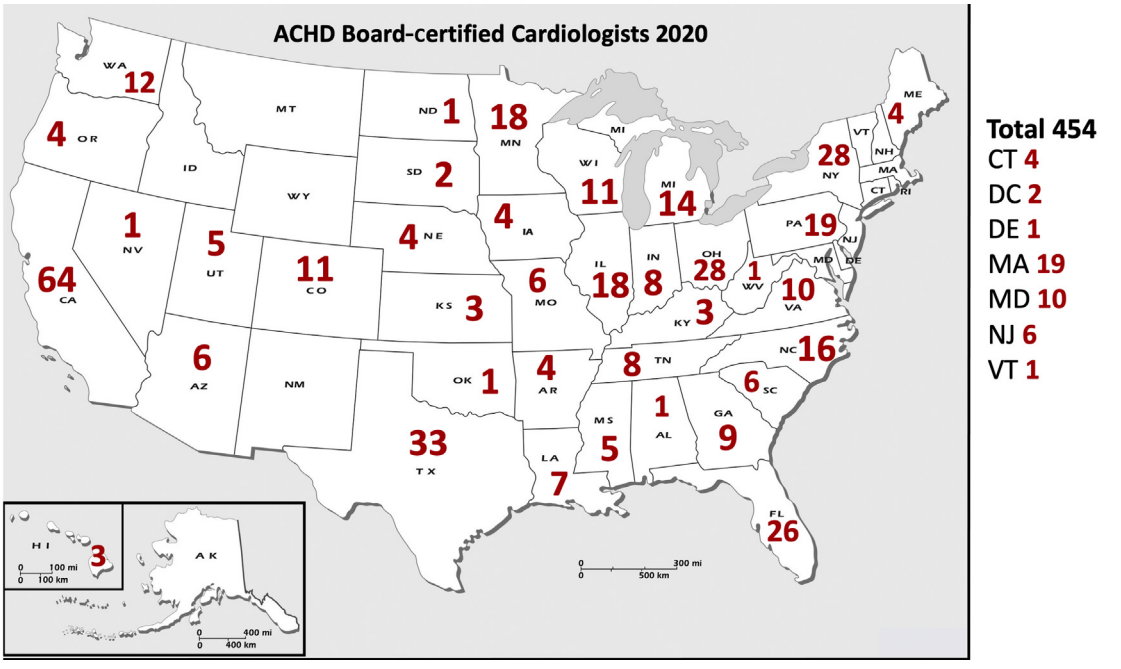

Fig. 1. US map with number of ACHD board-certified (BC) cardiologists per state. There are 455 ACHD American Board of Internal Medicine/American Board of Pediatrics BC cardiologists in the United States. Utilizing estimates from Marelli and colleagues,[33] the number of ACHD patients per state ranges from 158,000 in California to 2200 in Wyoming. Several states and territories have no ACHD BC cardiologists. In states with ACHD BC cardiologists, the ratio of ACHD BC cardiologist to ACHD patients ranges from 1/1254 in Minnesota, to states with large deficits, such as Alabama at 1/19,438; Oklahoma at 1/15,661; and Nevada at 1/12,433.

The ACHD cardiologist is an important and critical piece of the process to deliver high-quality ACHD care; however, the cardiologist is only a part of a larger team approach with multiple service and specialties necessary to deliver care. Attempting to estimate resources to match access and delivery of high-quality ACHD care is challenging.

PROGRAMMATIC RESOURCES

Determining the number of ACHD cardiologists and the number of other providers and support staff necessary for an ACHD program can be challenging. As well, determining the number of ACHD programs per population is equally challenging.

Although ACHA ACHD accreditation standards dictate the minimum number of programmatic resources, identifying program needs beyond accreditation standards need to take into account a program's spectrum of disease complexity, outpatient volume including locations of sites, and surgical and other procedural volumes, with consideration of the ACHD team role in inpatient care (consulting vs primary care team).

If it is assumed that most ACHD programs have an equal number of patients with CHD of simple, moderate, and great complexity,[23] the programmatic resources required for this population are likely to be similar or even more intense than for those cared for in primary care. In primary care, 1 in 4 patients have a chronic disease[18] and 37% of patients 65 years of age and older have a disability.[24] In this setting, it is estimated that it takes 21.7 hours per day to care for a 2500-patient panel.[25] It could be argued that there are few patients in ACHD that can be seen in the typical primary care appointment slot that runs 15 minutes or 20 minutes for a follow-up and 30 minutes for a new patient. Based on this assumption, a combined total of at least 3.0 full-time equivalents of ACHD providers (ACHD cardiologist and APP) would be required to manage an outpatient panel of 2500 patients. Shifting the less complex patients to the APP visit panel would allow an ACHD cardiologist the time to focus on the most complex of patients. Engaging a nurse coordinator and mental health professional to support the ACHD cardiologist and APP also is essential for success. ACHD programs that have a more complex patient panel mix, provide care at off-site clinics, and provide inpatient care, would require additional ACHD providers.

ADULT CONGENITAL HEART DISEASE CENTERS

Recognizing the challenges in providing appropriate care to ACHD patients, the ACC/American Heart Association (AHA) "2008 Guidelines for the Management of Adults with Congenital Heart Disease" were developed to emphasize the recommendation that "health care for ACHD patients should be coordinated by regional ACHD centers of excellence."[23] The concept would prove challenging until 2012 approval of an ACHD CV subspecialty certification.

Even without a formal recognition of CV subspecialty expertise in ACHD, the concept of regional centers began to develop organically after the 2000 Bethesda Conference.[26] In 2010, there were approximately 100 US ACHD centers; however, these centers were self-described centers of excellence.[27] The centers represented a broad spectrum of expertise, resources, and clinical volume, making the ability to demonstrate that these types of specialized centers improved patient outcomes.

In Canada, a federal mandate to shift ACHD care to a few specialized ACHD centers was associated with improved outcomes and survival.[28] Based on these recommendations, the "2018 AHA/ACC Guideline for the Management Adult with Congenital Heart Disease" continued to call for the development of centers of expertise and outline key personnel and recourses that should be part of the new programs.[29,30] Meanwhile, ACHA (a patient advocacy organization) was advocating for and exploring the possibility of a more formalized set of criteria for program's recognized as a regional ACHD centers. The Cystic Fibrosis Foundation had spearheaded efforts through program accreditation with improved outcomes.[31] Given this information, the ACHA began to take actions to move away from self-identified ACHD programs. In 2013, the ACHA had already put together a steering committee of ACHD experts and stakeholders to develop standards for ACHD program accreditation. The working group presented the final criteria for accreditation in 2014, which ultimately were endorsed by the ACC and the AHA.[32] In summary, the criteria for ACHA ACHD program accreditation requires each program to be committed to providing patient-centered care. They must have an adequate number of ACHD cardiologists, APPs, nurses, and social workers. They must have the ability to perform any surgery or procedure an ACHD patient might need at any given time, and they must be able to provide care 24/7.

Five centers participated in the ACHA ACHD accreditation pilot program in 2016 and in 2017 the program was open to all other US ACHD programs. At the time of this publication, 35 centers had completed the rigorous accreditation process (5 were in the process), which included developing

more than 100 policy documents, advocating for program resources, and passing a comprehensive site visit.

To date, the ACHA has not announced their goal for a total number of accredited ACHD centers, but data from Marelli and colleagues[33] can provide guidance. Fig. 2 illustrates the deficit in ACHD centers across the 52 US states and territories. The deficit was calculated by subtracting the actual number of centers per state from the estimated needs. The estimated needs were calculated using the following principles: geographic access to care and/or a minimum of 1 center for a population of 2 million, with the assumption that every ACHD patient should be seen at least once in an ACHD center.[33] Based on these criteria, a minimum of 100 accredited centers is required. Currently only 2 states have the required number of programs (Mississippi and Nebraska), whereas 6 additional states are close with the need for only 1 additional program (Oregon, Utah, New Mexico, Kansas, Wisconsin, and Connecticut). Four states (New York, Florida, Texas, and California) have the highest deficit, requiring at least 6 additional centers.

Fig. 3 captures both the current number and the deficit of ACHD centers. The distribution of current ACHD centers shows that 85% of the states in the United States have 0 to 1 center, with a gaussian distribution skewed toward the left. These states have either no deficit or a small deficit of 1 to 3 centers. It, therefore, is reasonable to predict that, were there to be the addition of only 1 to 2 additional ACHD centers in these states, distribution across the country would be substantially improved, shifting the gaussian distribution rightward, reflecting a higher quality of care across the United States. The greatest deficits in ACHD centers (deficit of $\geq$6 centers) are in states where ACHD centers already exist but in insufficient quantities. For these states, comprising approximately 15% of all states in the United States, a different approach to health services delivery of care planning is required.

Currently, there are vast stretches of the United States where ACHD patients do not have access to a specialty ACHD center. Given this, the focus should shift to increase the number of ACHA ACHD–accredited centers in areas that are underserved and develop strategies to support and advance these programs. Once the target areas are identified, ACHD providers and patient advocacy groups should work with state-level policy makers to remove barriers to care access and to support policies that provide incentives to ACHD

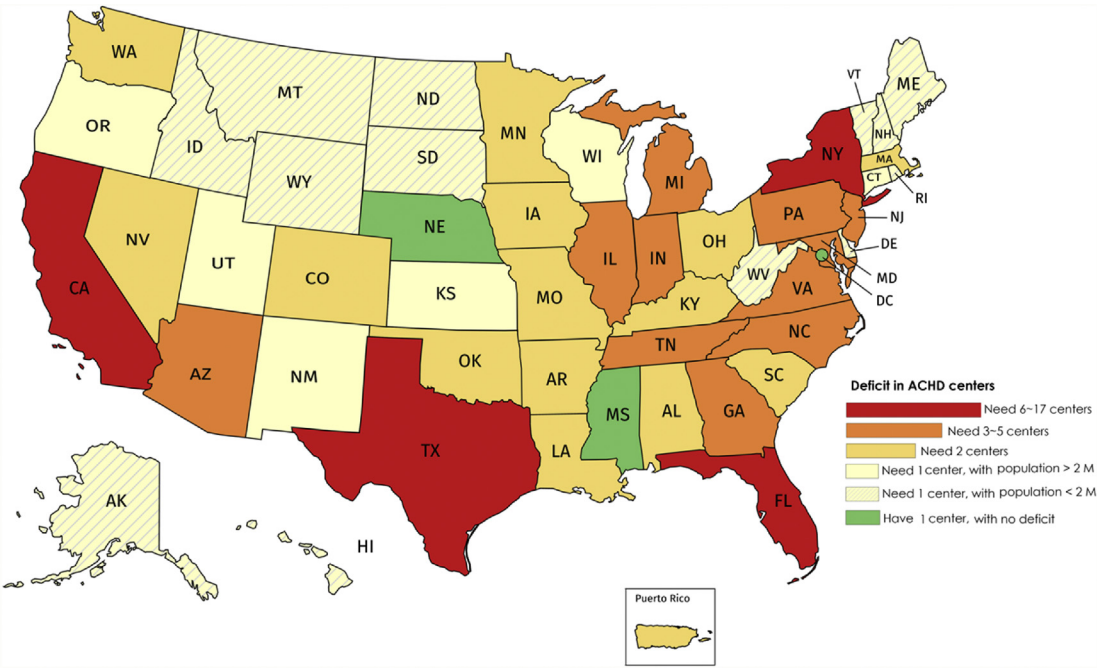

Fig. 2. Map of United States showing the gradient of deficit in ACHD centers per state, from the darkest red, representing a deficit of 6 to 17 centers, to green, showing no deficit with a minimum of 1 center. The states that are textured with diagonal lines are considered in need of an ACHD center for reasons of access rather than a number needed to serve a population of 2 million.

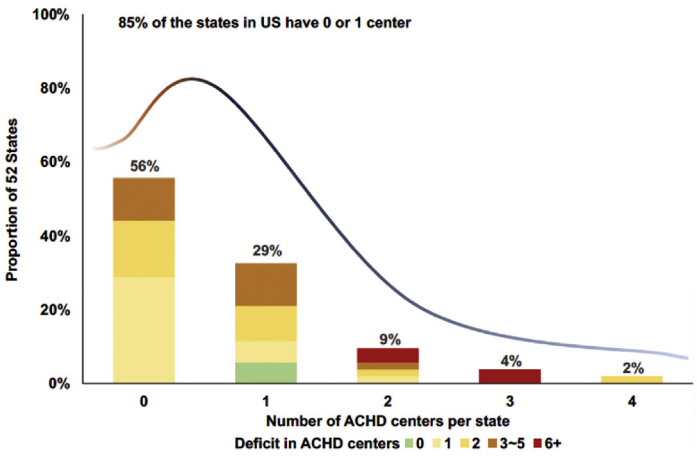

Fig. 3. Distribution of the number of ACHD centers per state and corresponding deficits. The X axis illustrates the current number of ACHD centers per state that vary between 1 center and 4 centers per state. Within each bar, colors indicate the deficit illustrated in Fig. 1 indexed to the actual number of ACHD centers per state. Notably, 85% of states in the United States currently have either no center or only 1 center, skewing the current gaussian distribution of ACHD centers toward the left.

cardiologists and other members of the ACHD team, to train and work in these underserved target areas. In addition, partnerships between ACHA ACHD–accredited centers and ACHD cardiologists practicing outside these centers need to be established and fostered. Since the Bethesda Conference in 2000,[26] the care of adults with CHD has seen tremendous advances, but there continue to be many ACHD patients without access to such specialty care. Given this, there still is much work to be done.

CONFLICT OF INTEREST

None.

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