

10-19-2021

## Health Care Policy and Congenital Heart Disease: 2020 Focus on Our 2030 Future

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### Recommended Citation

Chowdhury, Devyani; Johnson, Jonathan N; Baker-Smith, Carissa M; Jaquiss, Robert D B; Mahendran, Arjun K; Curren, Valerie; Bhat, Aarti; Patel, Angira; Marshall, Audrey C; Fuller, Stephanie; Marino, Bradley S; Fink, Christina M; Lopez, Keila N; Frank, Lowell H; Ather, Mishaal; Torentinos, Natalie; Kranz, Olivia; Thorne, Vivian; Davies, Ryan R; Berger, Stuart; Snyder, Christopher; Saidi, Arwa; and Shaffer, Kenneth, "Health Care Policy and Congenital Heart Disease: 2020 Focus on Our 2030 Future" (2021). *Division of Cardiology Faculty Papers*. Paper 90.

<https://jdc.jefferson.edu/cardiologyfp/90>

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CONTEMPORARY REVIEW

# Health Care Policy and Congenital Heart Disease: 2020 Focus on Our 2030 Future

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**ABSTRACT:** The congenital heart care community faces a myriad of public health issues that act as barriers toward optimum patient outcomes. In this article, we attempt to define advocacy and policy initiatives meant to spotlight and potentially address these challenges. Issues are organized into the following 3 key facets of our community: patient population, health care delivery, and workforce. We discuss the social determinants of health and health care disparities that affect patients in the community that require the attention of policy makers. Furthermore, we highlight the many needs of the growing adults with congenital heart disease and those with comorbidities, highlighting concerns regarding the inequities in access to cardiac care and the need for multidisciplinary care. We also recognize the problems of transparency in outcomes reporting and the promising application of telehealth. Finally, we highlight the training of providers, measures of productivity, diversity in the workforce, and the importance of patient–family centered organizations in advocating for patients. Although all of these issues remain relevant to many subspecialties in medicine, this article attempts to illustrate the unique needs of this population and highlight ways in which to work together to address important opportunities for change in the cardiac care community and beyond. This article provides a framework for policy and advocacy efforts for the next decade.

**Key Words:** advocacy ■ congenital heart disease ■ health care disparities ■ health care policy ■ health care workforce ■ value-based health care

The pediatric and adult congenital heart care communities face broad public health issues, including disparities in care, continuous increases in health care costs, and challenges with transparency in outcomes.<sup>1–3</sup> We recognize the importance of distinguishing congenital heart disease (CHD) within larger arenas of discussion, including through our collaborations with various pediatric and adult organizations and societies including the American Academy of Pediatrics, the American College of Cardiology, the American Heart Association, the Joint Council on Congenital Heart Disease, and the Congenital Heart Public Health Consortium. In this article, we attempt

to convene agendas on advocacy and policy issues for CHD, many of which have been identified and highlighted as a result of the COVID-19 pandemic (Figure).

CHD is the most common cause of birth defects and is one of the leading causes of morbidity, mortality, and resource use for congenital defects in the United States.<sup>2,4</sup> The disease spectrum is heterogeneous and is managed from fetus into adulthood with varied outcomes at different stages for individual patients. It is important to advocate for the needs of this population to achieve the best health care outcomes while optimizing resources. Contemporary conversations regarding congenital heart care focus on caring for the congenital

The opinions expressed in this article are not necessarily those of the editors or of the American Heart Association.

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### Nonstandard Abbreviations and Acronyms

<b>ACHD</b>	adult congenital heart disease
<b>CMS</b>	Center for Medicare and Medicaid Services
<b>RVU</b>	relative value unit
<b>SDOH</b>	social determinants of health
<b>STS</b>	Society of Thoracic Surgeons
<b>wRVU</b>	work relative value unit

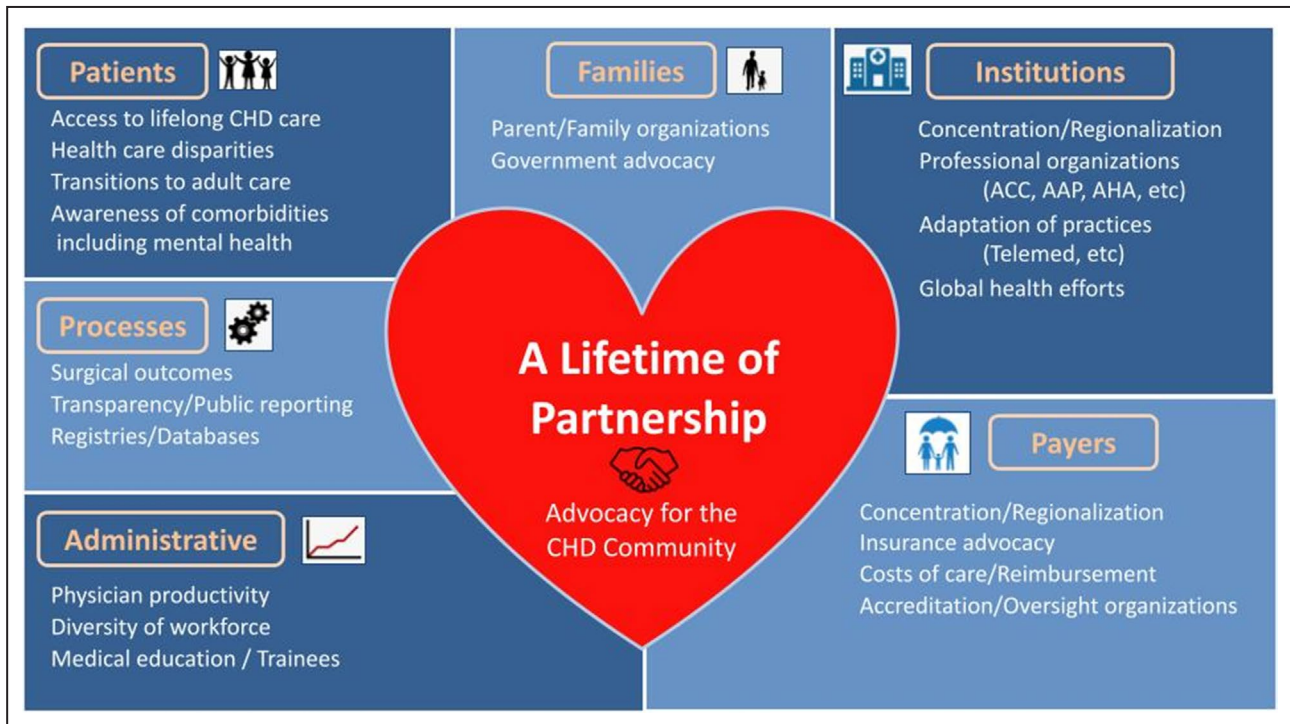
heart population into adulthood and assuring a smooth transition into adult care, consolidation and regionalization of procedural and surgical care, and the financial constraints of delivering multidisciplinary care to a highly complex population. The COVID-19 pandemic exposed many preexisting issues, especially those regarding diversity and disparities, equity in access to care, and questions of medical necessity and resource use. The pandemic prompted a sense of urgency regarding congenital cardiac community care and the need for advocacy for this vulnerable population.

Caring for children with CHD is resource intensive. Admissions for CHD cost an estimated \$5.6 billion annually. This comprises 15% of costs for all inpatient pediatric care despite accounting for only 3.7% of all pediatric admissions.<sup>5,6</sup> Nationally, 120 pediatric cardiac programs perform >40 000 surgical and

catheter-based interventions annually with significant variability in volume, outcomes, and costs at each hospital.<sup>7</sup>

During the past several years, stakeholder groups including professional organizations, patient/family organizations, and individuals have achieved key legislation and regulations that benefit the care and management of patients with CHD and their families. In 2018, the Congenital Heart Futures Reauthorization Act of 2017 (H.R. 1222/S. 477) was signed into law.<sup>8</sup> This legislation serves to enhance research and surveillance efforts at the Centers for Disease Control and Prevention toward the study of CHD and direct the National Institutes of Health to report on their ongoing research efforts. The Advancing Care for Exceptional Kids Act of 2019 was signed into law<sup>9</sup> in the same year as a component of the Medicaid Services Investment and Accountability Act of 2019 (H.R. 1839),<sup>10</sup> which benefits preexisting conditions such as CHD. This legislation aims to establish specially designed health homes for children with medically complex conditions and is voluntary for states, families, and providers. Furthermore, this bill mandates data and quality measure reporting for states and health homes, allows new payment models that better align payment with best outcomes, and includes a national definition for children with medically complex conditions including CHD.

Recent additional changes in care models and reimbursement have been catalyzed by the COVID-19



**Figure 1. Infographic.**

AAP indicates American Academy of Pediatrics; ACC, American College of Cardiology; AHA, American Heart Association; and CHD, congenital heart disease.

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pandemic. In March 2020, the Center for Medicare and Medicaid Services (CMS) announced new flexibility to provide telehealth services to beneficiaries regardless of originating site location. CMS issued a second final interim rule in April 2020 that included several key measures, including expanded access to COVID-19 testing and implementation of telehealth services requested by the American College of Cardiology and others from across the House of Medicine; the legislative and policy making body of the American Medical Association. This increased payments for virtual visits to match those for in-person office visits. These 2 simple modifications improved delivery of care and prompted efficient and cost-effective models that will influence health policy long after the pandemic has ended.

Value-based health care delivery prioritizes patient-centered care, optimizes outcomes relative to cost, and is distinct from programs designed to reduce cost or improve outcome alone. Although value has not been measured in the CHD population holistically, methods to optimize outcomes and reduce cost have been explored in specific CHD populations.<sup>11-15</sup> The congenital heart community has developed tools for self-examination and performance measures. Areas for continued progress include organizing our delivery “system,” efficiently sharing knowledge, and finding better ways to assess and communicate our performance to effectively increase value.

Although the concept of self-assessment is crucial to meaningful improvement, self-reporting is not entirely adequate. Alternatively, an externally organized, disinterested peer-conducted auditing process would seem preferable. With so-called Line Operations Safety Assessments inspections, there is precedent for such an approach in aviation, an industry with which congenital heart care is sometimes compared.<sup>16</sup> There is even precedent for such an approach in health care, as anyone who has ever been through a visit by the Joint Commission can attest. If restaurants are not allowed to inspect themselves, why do we think this is a good idea for congenital heart programs?

Unfortunately, although improving, publicly available outcome reports are imperfectly risk adjusted. Efforts to effectively educate the public or policy makers regarding the meaning of data have not kept pace with the release of information. Public reporting itself has often been the singular goal at the expense of enabling stakeholders to benefit from the information (patient and family education, direction of patients to high-performing centers, etc). The provision of information to the public has often oversimplified complex data, substituting clarity for accuracy. As an example, the concept of ranking is inherently artificial. It is unreasonable to summarize the performance and capabilities of a congenital heart center with a single number, conveying the erroneous concept that a center with

a score of 89 is inferior to one with a score of 90.<sup>17</sup> Improvements in the methodology of reporting and the effectiveness of educational efforts are possible,<sup>18</sup> and the United Kingdom experience provides both cautionary and instructive lessons.<sup>19</sup> Beyond public reporting, outcomes assessment should become the basis for systematic efforts at outcomes improvement.

## THE POPULATION WE SERVE: THE NEED FOR LIFELONG CARE

CHD is a lifelong disease with lifelong health care needs. These patients represent a cohort with several socioeconomic and systemic barriers preventing them from receiving care and optimizing health. Access to care can be improved by increased awareness of at-risk rural and urban communities, expansion of management facilities, and arrangement of consistent and stable follow-up (Table 1). Providing concentrated CHD care at specialized pediatric cardiac centers for children and adolescents is imperative as well as transitioning the care of young adults to adult providers with CHD expertise at specialized congenital cardiac centers.<sup>20,21</sup> Transitioning allows for advanced expertise and resources to manage complex patients.<sup>5,22,23</sup>

**Table 1. 2020 Call to Action: Advocacy Efforts in the Next Decade for Our Patients and Families**

### Accessibility

- Expand access for lifelong CHD care
  - Safeguard insurance coverage for children and young adults with preexisting conditions
  - Continue expanded private health insurance benefits for older children and consider additional expansion beyond age 25
- Develop models for improved portability of insurance benefits across state lines
- Increase attention in rural contexts and at-risk urban communities for efforts focusing on awareness, prevention, expansion of emergency management, and follow-up care
- Lifelong insurance for patients with CHD
- CHD and ACHD centers

### Funding

- Improve Medicaid funding by revisiting federal dollars as distributed to states
- Expand Medicaid for vulnerable populations including those with CHD
- Develop programs to advocate for Medicare parity within individual states with the goal of increased/appropriate reimbursement for services provided to Medicaid patients
- Address disparities created by balanced billing reform
- Research dollars: the Congenital Heart Futures Reauthorization Act, CDC, NIH, AHRQ and so on

### Issues related to the patients

- Address/assess health care disparities including consistency in care and resources available for minority populations
- Secure advances that improve transition to adult care
- Expand awareness of comorbidities including neurodevelopmental and psychosocial health
- Empowerment of patients and families through engagement of patients and families and patient/parent-led organizations

ACHD indicates adult congenital heart disease; AHRQ, Agency for Healthcare Research and Quality; CDC, Centers for Disease Control and Prevention; CHD, congenital heart disease; and NIH, National Institutes of Health.

Social determinants of health as well as institutional, financial, and neurocognitive factors have been identified as barriers to the successful transfer to adult congenital heart disease (ACHD) care.<sup>5</sup>

With increasing numbers of individuals with CHD surviving into adulthood, assuring access to high-quality inpatient and outpatient ACHD care is critical (Table 1). However, specialized centers are not available in all states. Patients often travel long distances for clinic visits<sup>24</sup> and incur significant expenses associated with travel, accommodation, meals, child care, and so on.<sup>25</sup> Management of CHD in vulnerable ethnic groups is even more challenging. Studies have demonstrated that the quality of care at primary care locations is sub-optimal, with fewer health resources, including fewer diagnostic imaging centers and offices for physicians, lesser diversity of physicians, and limited mental health providers, dentists, and other health practitioners.<sup>26,27</sup> To ensure that patients with CHD get adequate and equal access to lifelong health care, legislative support is required. The focus should be toward effective collaboration between the health care providers and insurance providers to ensure that patients with coexisting conditions are able to receive insurance and also facilitate expansion of insurance coverage to those aged >25 years (Table 1).

### Health Care Disparities and Social Determinants of Health

Longstanding systemic inequities (including historical systemic racism, institutional racism, implicit bias, among others) have resulted in differences in social determinants of health (SDOH) and delivery of care that has disproportionately affected communities of color. These inequities became very apparent in the COVID-19 era. To address quality and access to care, as well as health care delivery, policies must balance those differences in social determinants of health and systemic racism that exist and contribute to disparities in outcomes for CHD throughout the lifespan. Policies that seek to improve outcomes in pediatric CHD and ACHD care are critical for populations most profoundly affected by these disparities. These populations must be incorporated into the value-based care delivery model if such populations are to be appropriately served and not excluded. SDOH impact nearly all CHD and ACHD outcomes.<sup>28</sup> Infants born to women in low-income and lower education neighborhoods have higher odds of having CHD.<sup>29</sup> Maternal education and insurance status explains 33% and 27% of the relationship between race or ethnicity and poor outcome at 1 year of life.<sup>30</sup> In-hospital post-operative mortality rates are highest among Hispanic patients (3.9%) and lowest among non-Hispanic White patients (2.8%).<sup>31</sup> Furthermore, mortality rates in CHD persist among non-Hispanic Black patients and

Hispanic patients during the lifespan compared with non-Hispanic White patients.<sup>30,32</sup> In addition to SDOH, location of care and delivery of care in hospitals with higher reported mortality rates, lower rates of prenatal diagnosis,<sup>33</sup> implicit bias, and other such factors may further explain some of these racial or ethnic differences in outcomes. Accounting for SDOH, exposing institutional and implicit biases and diversifying workforce composition for the delivery of outpatient and hospital-based services can all be part of the larger solution to improve disparities in outcomes. Much can be learned from the efforts of other groups and from a deeper understanding of existing disparities.<sup>26,27,34</sup> The development of a diverse workforce, enhanced access to adult congenital providers, and expansion of easy access to translation services for non-English-speaking patients are all critical to improving outcomes.<sup>27</sup> Therefore, policies that specifically address biases, SDOH, and resultant health disparities in the pediatric CHD and ACHD populations are lacking and necessary.<sup>34,35</sup> Disparities may further be minimized by having balanced billing reforms (Table 1).

### Insurance

Limitations in access to care are influenced by insurance coverage and geography.<sup>36</sup> Among children and young adults with CHD, disparities may be further exacerbated by insurance coverage limitations given the presence of preexisting conditions. Historically, patients with ACHD have had a more difficult time obtaining health insurance.<sup>37,38</sup> With uninsured rates among children in the United States ranging from 3% to 5%, an uninsured child is associated with 2 to 3 times the mortality risk after surgical repair than their insured peers.<sup>36,39</sup> Sanders et al found that the percentage of uninsured among infants varied significantly by race and ethnicity: 11% of Asian infants, 16% of White infants, 17% of Black infants, 29.5% of Native American infants, and 29% of mixed-race infants were not insured.<sup>40</sup> Racial disparities in health provisions and insurance coverage influence early and long-term outcomes with higher mortality rates seen in Black and Hispanic patients following cardiac surgery. This is potentially influenced by geographical factors as this population may be referred for care in hospitals that have low surgical volumes and high mortality rates regardless of race.<sup>41</sup>

Policies to protect diverse communities including not allowing insurance companies to discriminate based on preexisting conditions or lifetime insurance caps are critical to reducing racial/ethnic disparities throughout the lifespan.<sup>42</sup> The Affordable Care Act<sup>43</sup> has provided major advantages to patients with ACHD as they now have the same rate of public and private insurance as their age-matched cohort.<sup>38,44</sup> The insurance through Affordable Care Act, however, is not

accepted by all hospitals, adding further challenges to the delivery of care for these patients. Even publicly and privately insured children or adults may have irregular care or complete loss of care. Changing insurance plans (whether attributed to changes in public insurance or parental employment) may necessitate changing medical teams or lead to gaps in care, likely altering outcomes.<sup>45</sup> Patients with ACHD with functional impairments find applying for Supplemental Security Income disability benefits unclear and challenging. There are very few specific diagnosis codes, such as cyanosis at rest or with activity, that qualify for Supplemental Security Income, thus many patients with ACHD who have other reasons for activity limitations are excluded. Providing insurance to patients with ACHD despite preexisting conditions and improved definitions for obtaining Supplemental Security Income would facilitate health care delivery and quality of life for this population (Table 1).

### Comorbidities

Poor neurodevelopment is a sequela seen in some patients with CHD and is associated with lower academic achievement, abnormalities in speech, and behavioral challenges in childhood.<sup>46</sup> These may limit educational opportunities and achievement and lead to decreased employability as an adult.<sup>37</sup> Access to high-quality coordinated care and early intervention may identify any limitations early and provide not only opportunities for rehabilitation but also provide realistic educational and career goals to the patient and family. However, across the United States there are limited centers with combined cardiac and neurodevelopmental clinics, making accessibility a challenge.<sup>47</sup> In addition, although neurodevelopmental interventions exist in pediatric care, these are further scant in adolescent and adult care, and therefore efforts need to be put forth to address these deficiencies.<sup>48</sup> The pediatric cardiologists should work in close association with pediatric neurologists and developmental specialists to ensure that patients receive collaborative care. This can be achieved by having established combined cardiac–neurodevelopmental clinics or having an efficient referral system to prevent any delays in intervention. Patients and their families should be adequately counseled about these comorbidities and their impact (Table 1). In addition, educators and school systems should be incorporated to ensure that individuals' cognitive and physical growth can be optimized.

Improved survival of patients with CHD has led to increased recognition and attention to extracardiac comorbidities.<sup>49</sup> These patients are at an increased risk of developing diseases affecting multiple systems such as liver, renal, and lung that require multidisciplinary care.<sup>50</sup> Access to adult subspecialty medical care is often challenging with patients struggling to find

providers who accept their medical insurance. There are specialized gynecologic and contraceptive requirements for patients with ACHD. Women of childbearing age with ACHD may have added risks of morbidity and mortality because of the effect of pregnancy-related hemodynamic changes on the heart. This includes complications of arrhythmias, heart failure, thrombosis, preterm delivery, and still birth.<sup>51</sup> Because there are specific gynecological and obstetric needs for such patients, collaboration with an ACHD specialist is imperative.<sup>51</sup> These women should be evaluated by ACHD specialists before conception so that high-risk women can be identified and can be counseled for appropriate management of complications should they arise. One other area of poor accessibility and use is dental care. There is overall poor awareness of the importance of dental hygiene in CHD and ACHD, with 1 survey showing that 38% did not know dental hygiene had any correlation with heart disease.<sup>52</sup> Barriers for dental care include dental anxiety as well as cost.<sup>53</sup> Pediatricians and pediatric cardiologists should regularly convey the importance of dental hygiene for these patients at every visit and should have established dental partners to ensure continuity of care. In addition, insurance coverage specific to dental needs should be provided to these patients with minimal deductibles or copayment so patients can use dental care with ease.

Psychological health issues, including anxiety, depression, and attention-deficit/hyperactivity disorder, are commonly associated with CHD, regardless of age and severity. Mental illness is associated with reduced quality of life and even premature mortality.<sup>54</sup> However, adequate psychological treatment and patient education is rare with limited access. Racial differences are seen in the diagnosis and treatment for psychological health.<sup>55</sup> In the long run, these limitations lead to repeated school absences, resulting in lower educational levels and decreased employment.<sup>56,57</sup> Policy makers, therefore, need to ensure sufficient access to high-quality mental health services despite the ethnicity of the patient and should have a particular focus toward those of lower socioeconomic status who may have other underlying stressors, such as systemic inequities, racism, and stigma surrounding anxiety and depression, which may result in a lower willingness or ability to seek care or self-report<sup>58,59</sup> (Table 1).

## DELIVERY OF HEALTH CARE SERVICES

### Portability

Health care policy, including the expansion of Medicaid coverage, may overcome geographic and racial differences in insurance coverage and lessen the divide between uninsured and insured infants.<sup>40</sup> This may be

achieved by improving Medicaid funding by revisiting federal dollars as distributed to states (Table 1). The pediatric cardiac community should actively advocate for these patients, as they are vulnerable and are often neglected during policy making. In addition, specific initiatives should be made and programs should be established that would advocate for Medicaid parity with the goal to increase reimbursement for the services used. This would provide improved access to quality care for children with CHD in all ethnic groups (Table 1). However, not all studies have found that federally supported expansions of health care eliminate all health disparities.<sup>36</sup> Widening gaps in coverage have been identified based on different ethnicities and among noncitizens, those speaking English as a second language, those without a college degree, and in those in families earning <300% of the federal poverty level.<sup>36</sup> Reimbursement from CMS through state-funded Medicaid programs for children and Medicare for ACHD has remained poor. Only recently, in March 2020, specialists for ACHD were finally recognized separately from general adult cardiologists for their specific skills and care provided to their unique patients by CMS through the use of a new specialty code.<sup>23</sup>

## Telehealth

An important development during COVID-19 included expanded use of telemedicine by many practitioners as the risks of leaving a safer home environment were weighed against the benefits of in-person office visits. Legislative changes resulting in significant payment increases for telemedicine delivery of care have allowed practitioners to interact with patients more efficiently, preventing hospitalization and potentially decreasing the need for more frequent testing. Before April 2020, telehealth had been available to seniors in Original Medicare who lived in rural areas but was limited to specific services.<sup>60</sup> Temporary policy changes in telehealth during the COVID-19 pandemic allowed patients to remain in their homes and receive care remotely and even across state lines. This model allows care for both established and new patients alike. Visits using both video and audio as well as audio only, in many cases, are billed for the same value as in-person visits.<sup>61,62</sup> These provisions through the final rule that expand telehealth coverage are temporary, yet congenital cardiologist and ACHD specialists praise the potential benefits of continuing this coverage for the patient population even beyond the COVID-19 pandemic. Because of the clustering of congenital cardiology specialists across a few cities in the United States, many pediatric and adult congenital patients have to travel hours or across state lines for routine follow-up cardiac care. Yet, with continued expanded coverage for telehealth visits and reimbursement

equivalent to in-person visits, the burden of access to health care and traveling long distances would be ameliorated. However, telehealth consultation may add to health care disparities and negatively affect the following populations: those belonging to lower socioeconomic backgrounds or living in rural areas, those with lower health literacy, those with limited access to technology, those with extremes of ages; children and elderly, and those belonging to vulnerable ethnic groups. Therefore, policy makers need to establish systems that may allow equitable telehealth services to all populations<sup>63,64</sup> (Table 2). Careful evaluation of the socioeconomic status and geographical feasibility of patients and their families should be done in addition to a patient's clinical condition to decide whether the patient may be evaluated in person or remotely.

Delivery of care in the ambulatory arena must remain agile, and the expanded use of telemedicine during the COVID-19 pandemic demonstrates how different practice models, funded appropriately, may extend care and improve efficiency. Limitations in care delivery related to prior authorization burden remains a significant concern for both ambulatory and inpatient services. Finally, transparency in reporting results will drive continued improvement in outcomes if it is appropriately managed in the coming decade (Table 2).

## Authorization Process

Prior authorization requirements have been developed by many payers with a goal to reduce practice variation and reduce overall costs. In the middle of a hospitalization or before leaving the hospital, use of these services sometimes requires approval from the payer before an appointment, test, or procedure is scheduled or a medication is prescribed. Unfortunately, the prior authorization process often becomes very inefficient related to the amount of time required by the

**Table 2. 2020 Call to Action: Advocacy Efforts in the Next Decade That Influence Delivery of Services**

- Reform/improve the prior authorization process: specific to CHD, peer-to-peer process to be only performed by congenital cardiologist, not be held accountable to adult guidelines
- Legislative for patient empowerment to have access to data
- Develop/expand platforms to facilitate transparency of data on outcomes from all institutions
- Developing a CHD dashboard with outcomes that are accessible to parents
- Develop mandated universal registries and databases that are funded by the legislative process
- Develop a fully integrated universal database
- Development of centers of excellence for CHD
- Extend/enhance reforms initiated during the coronavirus pandemic including telehealth programs
- Establish/define parameters for "value" in the care of patients with CHD
- Use metrics to assess quality of life in CHD

CHD indicates congenital heart disease.



practitioner and their colleagues to process the requests and address the appeals. Many practices have had to designate  $\geq 1$  individuals whose sole job is to apply for prior authorizations, increasing costs of the practice. Many authorizations may take days to weeks to process, delaying care and necessary treatment. Prior authorizations often result in peer-to-peer conversations with physicians who are not familiar with CHD; therefore, these time-consuming and inconvenient conversations are actually peer-to-nonpeer conversations. Finally, the prior authorization process is meant to focus on indicated treatments and testing for a particular patient; this becomes difficult when faced with a very heterogeneous cohort that lacks large studies with backing of evidence. The "Patient over Paperwork" initiative was created in CMS by The Office of Burden Reduction and Health Informatics in 2017. This office showcased the continued efforts by CMS during the COVID-19 pandemic to help reduce burdens placed on health care providers. The approach of "Patient over Paperwork" should therefore be adopted by health care systems to ensure that patients' diseases are appropriately managed without unnecessary delays or added costs (Table 2).

### Inpatient Services

For many practices, hospital-based services, including cardiac catheterization, cardiac electrophysiology, and congenital cardiac surgery, are key drivers in their financial sustainability. Neonatal heart surgery in particular carries a high hospital cost and collection per patient.<sup>1,65</sup> These hospital services provide financial support at many children's hospitals which in turn compensates for other less lucrative but essential practices. Despite the strong financial support for programs that offer these invasive procedures, considerable advocacy efforts remain needed. For instance, balloon septostomy for transposition of great arteries, first performed by pediatric cardiologists in 1966, was only recently established as a billing code with a work relative value unit (wRVU) definition. This required efforts by multiple organizations, including the Society for Cardiovascular Angiography and Interventions.

The ongoing COVID-19 pandemic has impacted all of these issues, affecting inpatient practices. Shutdowns of elective procedures for weeks to months depending on the location had a considerable effect on children's hospitals, requiring furloughs, reductions in staffing, salary cuts, or other benefit adjustments to balance finances. Even as many programs have begun to increase elective procedures, changes have been necessary in normal processes to ensure the safety of the patients and staff. For instance, turnover time in procedure rooms has changed because of the need for a certain time of air exchange after

aerosolizing-generating procedures, extending time in the procedure rooms and longer staff work hours.

### Cardiac Surgery

During the past 60 years, the outcomes of surgery for CHD have improved remarkably. Early technical innovations, including the Norwood procedure,<sup>66</sup> the arterial switch operation,<sup>67</sup> and the Fontan procedure,<sup>68</sup> have yielded ever-improving results consequent to steady multidisciplinary advancements in surgery and perioperative care.<sup>69</sup> Despite the progress, success is not uniform and universal, and outcomes continue to vary by surgeon, by center, and by patient.<sup>1,7,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84</sup> Understanding that variability, its underlying causes, and how to improve the outcome of every patient remains the primary challenge.

Cardiothoracic surgeons, through the development of the Society of Thoracic Surgeons (STS) databases, were early adopters of systemic outcomes monitoring, beginning with adult cardiac surgery.<sup>85</sup> However, the heterogeneity of procedures performed in children and the relative rarity of even the most common procedures presents challenges to performance assessment. This is different in adult cardiac surgery, in which a much smaller variety of procedures are performed at least an order of magnitude more frequently.<sup>86,87</sup> Despite the challenges, there is now a widely embraced goal of programmatic transparency, manifested in public reporting by the STS itself, as well as various efforts at the state level, and the "performance" ranking of centers such as the annual *US News and World Report* survey.<sup>88</sup> It should be noted that STS supports the rating of programs (ie, with ratings of "better than expected performance," "same as expected performance," or "worse than expected performance").

The provision of care to patients with CHD is among the most complex endeavors in medicine, with a well-understood relationship between volume and quality of care.<sup>1,89</sup> Dilution of expertise and experience associated with an excess number of programs is a major barrier to improvement. This may be driven by a larger financial incentive as often cardiac surgery programs support several other pediatric specialties.<sup>1,65</sup> Regionalization of congenital cardiac care has recently been advocated in the United States.<sup>17</sup> It has been evaluated in pediatric cardiovascular care in a simulated manner and has demonstrated that 67% of low-volume CHD hospitals are within 25 miles of a larger volume CHD hospital, suggesting that travel distances for patients could be reasonable in a regionalized system.<sup>14</sup> Johnson et al published the first simulation showing that care at a high-value center for a rare, high-risk CHD lesion may confer significant outcome improvement and cost savings.<sup>15</sup> Conservative estimates suggest an overall

reduction in operative mortality of 12% to 15%, achievable without significant reductions in patient access.<sup>90</sup> Again, the experience of other countries may be instructive as to both the potential pitfalls and the potential benefits to children with CHD.<sup>91-93</sup>

### Collaborative Knowledge Sharing

Traditional methods of sharing advancements in medical knowledge, based on single-center experience, have significant limitations that have greatly inhibited progress. To overcome these problems, multicenter learning initiatives must be undertaken. As an example of such a project, the National Pediatric Cardiology–Quality Improvement Collaborative has recently initiated a “surgical coaching” project to facilitate mutual site visits to enhance sharing of collective knowledge. The challenges of COVID-19 may similarly benefit from multicenter learning initiatives to establish more standardized approaches to the performance of “elective” pediatric cardiac surgical procedures.<sup>94</sup>

Professional societies and leaders in the field are beginning to evaluate standards of care models that would define the resources that an institution must have to perform various types of surgeries; such examples currently exist for neonatology and pediatric surgery.<sup>95,96</sup>

Knowledge sharing has been described in quality collaboratives with evidence of improved outcomes in those centers involved by sharing best practices for high-risk populations among members.<sup>11,13</sup> A subsequent cost analysis of the effect of knowledge sharing showed a 27% cost reduction after implementation of the practice change suggested by the collaborative.<sup>12</sup>

Registries and databases function as repositories of important clinical and administrative information for various uses, including clinical, population-based epidemiologic, and outcomes research; accreditation; education; quality improvement; advocacy; and public reporting for administrators, care providers, advocates, and patient and parent consumption.<sup>97-99</sup> To be efficient, most registries are narrowly defined with a variable amount of data and data detail collected, typically only covering a short span of time. Some databases may be more broad based or administrative and lack clinical depth. Unfortunately, a multiplicity of goals and objectives have led to a plethora of databases gathering data on the pediatric and adult congenital cardiovascular population. Most academic centers participate in a combination of databases with rising levels of frustration because of the combined large costs and an unclear return on investment from participation. The cost is generally not related to the initial or supplemental costs to joining the registry or database, but attributed to the personnel costs required to obtain the data that will be sent to the data repository. Of course, one could argue that the investment of this money and time and

effort will actually save tremendous money and time and effort by eliminating the need for expensive, time-consuming, and labor-intensive ad hoc exercises in gathering data every time a new need exists for data, whether that need is to complete a request for data from an insurance company, governmental agency, or hospital regulatory body. Integrating databases is a very useful potential means of allowing multiple data repositories to collaborate meaningfully and reduce burden of data entry (Table 2). Such integration can be achieved by linking databases together or by creating a single software that allows submission of data to multiple registries with a single act of data entry. In a health system environment that is already struggling with cost containment, individuals and particularly smaller programs may not have adequate resources to participate in the large panel of repositories. The large data harvests resulting from such efforts may be skewed representing efforts and outcomes at several large centers and may not be generalizable to smaller centers. The development of high-value platforms that address some of the issues learned from previous registry efforts and successes requires collaboration of multiple specialties involved in pediatric and adult congenital cardiovascular care, including cardiovascular programs of variable types and sizes.<sup>100-106</sup> One way to make these data sets more robust would be to include mechanisms to track outcomes and use them internally as well as collaboratively for quality assurance and improvement purposes (Table 2). As a field, our goal remains to deliver the best care in efficient high-reliability, high-value settings and to report outcomes transparently. To do so, meticulous forethought into integrating and streamlining databases that capture the entire course of a patient’s life course is critical to provide the highest value care to the large, high-risk pediatric cardiovascular population.<sup>107</sup> It is also important that these databases be available to all institutions and be funded at a federal/state level to provide equal access to all participants (Table 2).

Transparency and public reporting have taken on increasing importance as evidence suggests that outcomes are not uniform across all organizations and vary based on center volume and physician-level factors.<sup>108-110</sup> Currently, in the United States, there is no central authority that mandates the number of procedures or surgeries a center must perform to be accredited in caring for patients with CHD. Outcome sharing and transparency is an important component of the shared decision-making process that families and physicians undergo when choosing the best treatment for their child based on available data and on specific preferences of the family.<sup>109,111-114</sup> Multiple challenges exist to reliably reporting outcomes and measuring the quality of an institution, including accounting for inherent higher risk patients who may at baseline have poorer

outcomes. Improving public reporting will require the creation of an easily accessible, accurate, centralized repository that accounts for case volume, disease complexity, and valid definition of both short-term and long-term outcomes (Table 2). Patient-based and parent-based pediatric and adult congenital advocacy groups recommended that (1) collected data points be centralized, have standardized key variables, be validated, and include benchmark lesions, short-term and long-term outcomes, and patient and family experiences; (2) interpretation be risk adjusted and differentiate centers with supportive materials explaining in lay terms how to interpret the data; and (3) presentation be publicly reported, easily accessible, and presented by geography/region and diagnosis. There has been a recent call to embrace regionalization of care to improve national outcomes from pediatric cardiologists, pediatric cardiothoracic surgeons, ethicists, and patient/parent groups.<sup>7,17,114,115</sup> To accomplish these goals, collaboration and engagement must be with a diverse group of stakeholders, including physicians and other caregivers, hospital administrative leadership, professional organizations, insurance companies, community members, families, and legislators.

### Value-Based Care in CHD

CHD management throughout a lifetime is resource intensive, although its prevalence is quite low, with the use of 23% of the global health resources leading to increased health care burden.<sup>116</sup> According to CMS, the national health expenditure grew 4.6% to \$3.8 trillion in 2019, or \$11 582 per person, and accounted for 17.7% of the gross domestic product.<sup>117</sup> The expenditure per person was found to be twice that of comparable countries.<sup>118</sup> To address this increasing burden of health expenditure, policies and strategies should be employed toward containing costs that are spent on health care services provided, insurance coverages, public health, and research (Table 2). Lessons can be learned from other high-income countries that have successfully achieved cost containment. France, the United Kingdom, and Germany have all employed strategies that have helped contain costs. These include public budgeting, price setting, budget cuts. They also used a value-based approach through activity-driven costs and use of technology assessments.<sup>119</sup> Value-based assessments measure outcomes that matter to patients during the full cycle of care relative to the costs to achieve those outcomes.<sup>120</sup> Higher value occurs when outcomes are improved relative to the cost to provide care for a given condition. This may occur by improved outcomes with cost maintenance, by significantly improved outcomes at a marginally increased cost, or by maintenance of excellent outcomes at a lower cost. There are significant data on assessing outcomes and cost independently but not as a single value

metric. Outcomes such as mortality, length of stay, and prevalence of complications worsen as lesion complexity increases.<sup>1,108</sup> Prior reports examining the relationship between hospital volume and outcomes have shown that mortality decreases as cardiac surgical volume increases for high-risk operations, even when adjusting for patient-level risk factors and case mix.<sup>121</sup> Similar to outcome, total hospital cost varies by lesion complexity, increasing with higher lesion complexity.<sup>1</sup> Cost also varies widely by hospital. The variation in cost by hospital has been investigated, and one-quarter of the variation in cost by hospital can be explained by differences in length of stay and complication rate.<sup>1</sup> All of the important data required to begin to move to value-based health care delivery in pediatric cardiovascular care are currently in place. Data from reliable outcome registries and administrative databases may be linked effectively to report value-based assessments transparently and publicly. These value-based assessments will significantly impact where parents, payors, and providers seek or refer patients for pediatric cardiovascular care.

One such important assessment of value is the assessment of health-related quality of life (HrQOL), which assesses various functions: physical, psychosocial, emotional, social, and school. With diagnostic and surgical advancements, many children survive into adulthood, therefore the assessment of HrQOL is an important indicator of the overall health of the patient. Many HrQOL have been done on teenagers and adults, but very few on younger children. A multicentre prospective cross-sectional study by Abbasi et al investigated the HrQOL in children of ages 5 to 7 years, with and without CHD. Although the perception of HrQOL of patients with CHD was similar to health controls, the parents of patients with CHD reported a lower HrQOL compared with parents of healthy children.<sup>122</sup> The discrepancy in HrQOL reported by parents and children can indicate the differences in attitudes and perceptions toward the disease and therefore requires family-centered approaches toward managing these patients. Quality improvement projects are important in assessing current practices and optimizing patient outcomes, experiences, and values. Health care systems should therefore constantly invest in obtaining data regarding the health and quality of life of patients and carry out research studies to analyze these data and ensure that a dynamic approach is used in bringing change in the provision of care based on the findings (Table 2).

### THE PROVIDERS OF CARE: WORKFORCE

Providers of care for the CHD population will also see several changes in the coming decade as health policy

develops. Advocacy for a diverse workforce, appropriate evaluation of provider productivity, and expanded funding for training programs at all levels will advance provider security and job satisfaction. Ever-specialized advanced care providers may be necessary to augment a limited workforce as traditional delivery models are retired.

## Training the Workforce

During the past decade, physician shortages are predicted as high as 121 000 by 2030, with projected shortfalls in non–primary care specialties >40 000.<sup>123</sup> This is largely cited as being attributed to physicians entering retirement combined with an aging patient population with greater health care needs. Despite these predictions, pediatric cardiology has remained a competitive subspecialty. Categorical pediatrics has gained positions every year since 2005, with a record high of 2864 positions offered in 2020 and a 98.2% fill rate.<sup>124</sup> The number of applicants to US pediatric cardiology fellowships has exceeded available positions every year since at least 2006. This has occurred despite a steady increase in pediatric cardiology fellowship training programs from 45 programs offering 100 positions in 2006 to 59 programs offering 158 positions in 2020.<sup>125,126</sup> However, warning signs exist: the ratio of applicants to available training spots has steadily decreased from a peak of 1.6:1 in 2008 to 1:1 in the most recently completed match. This past year's match also saw a record 12 programs go unfilled, with 47 of 59 programs reaching their quota in the match and a record low of 14 applicants not obtaining positions. Applications have held steady at ≈160 to 170 per year while training positions are increasing. It is imperative that we envision fellowship positions as a critical component of the national—and perhaps international—workforce and not merely a solution to local institutional manpower demands. During the past year, fellowship programs saw new challenges in recruitment given the current limitations to in-person interviews. The most recent assessment of the pediatric cardiology workforce was published in 2015, which demonstrated a tightening in the job market with 142 jobs filled/year from 2014 to 2015.<sup>127</sup> The majority of 2015 survey data respondents rated the relative ease of obtaining a job after 3 years of core training as “somewhat difficult.” Respondents rated obtaining jobs in interventional cardiology and electrophysiology as the most difficult, whereas those seeking positions in cardiac critical care, ACHD, and heart failure/transplantation rated the experience as “somewhat easy” to “extremely easy.” Imaging positions were in the middle ground. The authors estimated that 135 jobs/year would be needed subsequent to the survey, falling short of the number of fellowship graduates per year. Furthermore, this survey

highlights the need to better define the workforce so that we can better meet patient needs. Perhaps the most urgent example is growing our ACHD workforce. Secondary to American College of Cardiology advocacy efforts, ACHD became a boarded subspecialty in 2012, and the board certification examination began in 2015. As of 2019, there are 455 board-certified ACHD providers serving the needs of 1 to 1.3 million adult patients with CHD.<sup>128</sup> Before 2019, this certification could be obtained by physicians through either the training pathway or the practice pathway. The training pathway consisted of a 2-year ACHD fellowship, and the practice pathway consisted of physicians who were trained in adult or pediatric cardiology without formal training in ACHD. However, since the beginning of 2021, it is mandatory for physicians pursuing ACHD to have a 2-year fellowship. This poses some challenges that require physicians to revise training approaches to meet the growing needs of ACHD care. First, there are only 24 Accreditation Council of Graduate Medical Education–accredited fellowship programs across the country. Second, there are unfilled spots in these programs, as ACHD is not among the most interested subspecialties.<sup>129</sup>

Therefore, a repeat pediatric cardiology workforce assessment is essential to accurately gauge our current workforce numbers and optimize training program numbers in both categorical and subspecialty positions. Furthermore, the infrastructure should be developed among division chiefs, private practice medical directors, and fellowship program directors to collect these data efficiently in an ongoing fashion to guide the availability and curricula of fellowship programs (Table 3).

Advanced practice providers have become key players in the pediatric cardiology workforce, particularly

**Table 3. 2020 Call to Action: Advocacy Efforts in the Next Decade That Improve the Workforce**

- Align fellowship training opportunities with workforce demand
- Develop the infrastructure to rapidly obtain, analyze, and report workforce data
- Increase efforts to diversify the workforce to better represent and care for the populations served
- Support gender and race/ethnicity equity in career advancement opportunities
- Enhance training programs with greater attention to issues of health equity and the impact of racism and sexism on conscious/unconscious bias and its impact on health care delivery
- Support the education and development of advanced practice providers
- Enhance research funding and develop models for improved collaboration
- Expand advocacy to address administrative issues in the workforce
  - Optimize EMRs/documentation for provider as well as administrative satisfaction
  - Improve provider productivity definitions and academic productivity definitions
  - Expand technology services to better serve the workforce

EMRs indicates electronic medical records.

with the expansion of cardiac intensive care units. Of the 112 hospitals with pediatric cardiothoracic surgery programs in the STS database, 104 programs have advanced practice providers in the cardiac intensive care unit.<sup>130</sup> However, unlike the well-defined physician training programs, there is no standard path of training or pediatric cardiology or cardiac intensive care unit curriculum for advanced practice providers.<sup>130</sup> Moving forward, there should be clearer educational paths and curriculum for advanced practice providers entering the field of pediatric cardiology (Table 3).

In addition to medical workforce needs, the STS Workforce on Congenital Heart Surgery has conducted practice surveys every 5 years to identify and address surgical workforce needs. In addition to identifying practice information, these surveys have been also instrumental in driving necessary approvals for surgical therapies for our unique patient population such as US Food and Drug Administration approval for pediatric ventricular assist devices.<sup>131</sup> Congenital cardiac surgery became a recognized fellowship by the Accreditation Council of Graduate Medical Education in 2007 with board certification offered through the American Board of Thoracic Surgery.<sup>132</sup> In 2020, there were 12 applicants for 11 positions offered at 11 programs with a 91% fill rate.<sup>133</sup> Fellows identified mentorship, rotation as a trainee, and surgery viewing as the primary motivations to pursue a career in congenital cardiac surgery.<sup>132</sup> In 2015, there were 297 active congenital heart surgeons in the United States and Canada with a 61% survey response rate to the workforce survey. Most respondents worked in a metropolitan area (77%) with 2/3 holding academic affiliations, participating in Accreditation Council of Graduate Medical Education accredited training, and participating in research. Although there was a trend toward higher individual case volumes compared with prior years, 51% of respondents felt that there were too many individuals practicing in the same geographic area. The majority of congenital cardiac surgeons report good job satisfaction and financial stability upon retirement, with the expected age of retirement being 67±5 years.<sup>131</sup>

### The Diversity in Workforce

During the past 15 years, there has been an increase of women entering medicine, such that most medical students are now women. In 2016, women comprised 72.9% of pediatric residents and 50.5% of pediatric cardiology fellows.<sup>125,127,134</sup> Although there is an increased parity of women in training, the number of women practicing as pediatric cardiologists was still just 34% in 2016,<sup>134</sup> and in adult cardiology, there is a 37% disparity in career advancement for women compared with men at similar career levels.<sup>135</sup> Although 34% of the pediatric cardiology workforce consists of

women, leadership positions, such as division chiefs, are male dominated. In addition, the 2018 Doximity Physician Compensation Report highlights a 15% wage gap for women compared with men in pediatric cardiology.<sup>136</sup> This may in part be reflective of higher proportions of men entering invasive subspecialty jobs such as cardiac catheterization and electrophysiology or be attributed to accelerated career advancement compared with female colleagues. As part of the ACC's mission to improve fairness in compensation, they have developed several compensation tools that are freely accessible.<sup>137</sup>

Although it is an interesting question as to whether the percentage of women in pediatric cardiology should best mirror the gender makeup of pediatric residents as a group or that of our patients, we face a more significant problem with racial diversity in the field. In 2016, the US population was 62% White, 5.2% Asian, and 31.9% underrepresented minority groups (including Black, Hispanic, Native American, and Pacific Islander), and the latter group represented only 16% of pediatric residents.<sup>134</sup> Underrepresented minority groups comprise an even smaller percentage of pediatric cardiology, with a slight increase among fellows from 7.7% in 2006 to 9.9% in 2016 and a similar increase in practicing pediatric cardiologists from 5.8% to 7.8%.<sup>134</sup> Furthermore, the ethnic diversity of faculty is almost nonexistent at the leadership level in pediatric cardiology.

Beyond this, retaining women and pediatric cardiologists of different ethnicities in academic heart centers is also of critical importance. Mounting evidence suggests that when physicians and patients share the same race or ethnicity, this improves medication adherence, shared decision-making, patient retention, and patient perceptions of treatment decisions. Not surprisingly, implicit bias from the physician has decreased.

Women currently comprise 5% of practicing congenital cardiothoracic surgeons but represent 20% of cardiothoracic surgery residents.<sup>138</sup> Women report similar career satisfaction to men but are less likely to perform research during their careers and less likely to be married or have children.<sup>135</sup> The majority of female and Black patients reported explicit bias within the cardiothoracic surgical community in a recent survey of the members of the STS.<sup>139</sup> Women also have more difficulty in retention and promotion than their male colleagues.<sup>138</sup> This is especially pronounced in Black female surgeons, with <8% of these academic surgeons holding the role of full professor.<sup>140</sup> Mentorship in Surgery programs has been cited as an essential component to advancement for women and those belonging to vulnerable ethnic groups.<sup>141</sup> In a survey seeking to explore ways to improve diversity and inclusion within the STS, the need for both culture change and mentorship emerged as critical areas.

Studies have shown that increased diversity leads to improved critical thinking<sup>142</sup> and improved scientific research products.<sup>143</sup> In the business sector, the highest yield for increasing diversity has been college recruitment efforts and dedicated mentorship programs.<sup>144</sup> We must strategize ways to increase interest in pediatric cardiology among medical students and residents of all ethnicities. This may be achieved by early exposure during training; loan forgiveness, particularly for the lengthy training required in pediatric cardiology subspecialties; and allotted research time aimed toward research efforts.<sup>143</sup> In addition, making sure that institutional, regional, and national CHD initiatives and policy statements prioritize health equity and include distinct leadership roles for underrepresented minority trainees and faculty who undoubtedly bring a different perspective to the table than the status quo. We must continue to strive for expanded diversity in the field for all of these reasons so that our workforce reflects the population it serves (Table 3).

### Assessment of Provider Productivity

Physician productivity can be difficult to measure. If focused on purely clinical work, the wRVU system is most commonly used to assess the amount of work done in a particular specialty.<sup>145</sup> The wRVUs do not always reflect the time and effort spent with complex patients in the outpatient space. This is particularly challenging while evaluating ACHD. Notably, wRVUs will differ considerably across specialties and between procedural and nonprocedural visits. For instance, a pediatric transplant cardiologist has very few billable codes outside of clinic visits—for this specialty, use of a wRVU system will be ineffective. These issues become important in the calculation of salaries for the practitioners involved. In the Merritt Hawkins 2019 review of physician-recruiting incentives, 70% to 75% of physicians were paid a base salary with some form of bonus.<sup>146</sup> The metric to obtain a bonus was based on wRVUs in 70% of these cases. The base salaries themselves are commonly derived from published data from the Association of Administrators in Academic Pediatrics, Association of American Medical Colleges, or Medical Group Management Association models. Academic rank commonly plays a large role in the salaries as well, depending on the institution. It is important to note that in a pediatric cardiology group with all subspecialists, it is critical to have breadth and depth in all areas, independent of wRVUs. For example, optimal and outstanding care requires general pediatric cardiologists who provide outpatient care, generally associated with lower wRVUs, as well as interventional cardiologists, who tend to generate a greater wRVU load.

Productivity measures will be exceedingly difficult to assess this year; for instance, if a pediatric cardiologist is pulled to cover adult intensive care unit care

for patients with COVID-19, how does that time count against their wRVU goals? With fewer surgeries and procedures, can any “normal” goals be used at any institution? Because of financial pressures, many organizations have had to place holds on hiring, with delays in training and academic advancement also expected. In light of these COVID-19–related issues, it is likely that some changes in the way wRVUs are assessed will be needed in the field. Assessments of quality and timeliness of care could be considered as a part of a new model, which will need to be flexible enough to account for the ongoing, undulating course of the current pandemic (Table 3).

Involvement in research and teaching are imperative to physicians and require time and effort. However, as there is often no objective way to measure one's involvement in research and teaching other than a number of publications and grants, these contributions are often undermined.<sup>147</sup> The RVU, therefore, can be used to assess academic productivity, which includes research and teaching. However, its application and calculation can be tedious as there are multiple forms of teaching, and equating the time and effort put in these can be difficult. For example, how can giving an hour-long presentation to 200 students and residents at a grand round be equated to providing a 40-hour weekly bedside clinical teaching session to 5 students? It is these challenges that have led different academic institutions and departments to adopt different metrics for RVUs, which leads to inconsistencies in assessment. Despite these challenges, Mezrich and Nagy developed a web-based academic RVU system that assigned weights to different elements of academic activities so as to develop an academic RVU for administrative work and community services, research, and teaching.<sup>148</sup> Although these weights are arbitrary, if applied to all physicians equally, they can generate meaningful results reflecting academic productivity.<sup>148</sup> It is evident that RVUs can provide an objective method of calculating work contributed by the physicians, and therefore programs must employ careful weights to every activity to ensure appropriate calculations (Table 3).

### Role of Patient–Family Centered Organizations in Advocating for Patients With CHD

The Congenital Heart Public Health Consortium, formed in 2009, is an organization that maintains public–private partnership consisting of all stakeholders involved in the care of children with heart disease and strives to contribute to bring change in the lives of these children through advocacy and public health initiatives.<sup>149</sup> The consortium consists of 200 individual and organization members, including academic and parent-led

organizations and federal agency representatives. In addition to coming together in the consortium, these patient-centered and family-centered organizations are catalysts in advocating for children with CHD as they are passion and mission driven. Implementing solutions is an important responsibility, and these organizations can collaborate with health care providers and facilities to help implement solutions.<sup>2</sup> One of the issues identified in this article and other literature is the barriers to lifelong care for children with CHD and the management of other comorbidities. These organizations can help create awareness in the families, on individual and population levels, to ensure that they recognize the need for multidisciplinary and lifelong care. This includes early identification of neurodevelopmental disabilities and timely intervention (Table 1). Another area of contribution can be creating awareness of the importance of transition of care to ACHD services.

In addition, these organizations can be key players in putting their efforts in prevention of CHD. Gestational diabetes and infectious diseases are important risk factors for CHD, and therefore appropriate screening of gestational diabetes, timely fetal echocardiograms, and education of women about the management of these diseases can help reduce the incidence of CHD among newborns. This will require close collaboration with the obstetrics and gynecology departments.

## 2020 TO 2030 VISION

As we enter the next decade, the field of CHD care has an obligation to review the lessons of the prior decade and lead the charge on forward looking to patient-centered, value-based care for our patients. Issues related to health care policy in patients with CHD become a focus for the many stakeholders involved. CHD will continue as the most common cause of birth defects and a leading cause of morbidity and mortality and resource use. During the past couple of years, there has been significant but limited progress in aspects of health care policy as evidenced by recent legislation demonstrating effective advocacy. For progress, continued work will be needed to build on these improvements, particularly as we evaluate issues that were exposed during the COVID-19 pandemic.

Moving forward, the focus of our efforts in the next decade should encompass the issues laid out in this article. Importantly, all stakeholders should be involved in creating goals and policy. The patients with CHD themselves and their families will continue to be important drivers of this advocacy agenda. Most of the efforts outlined revolve around access to care, affordability, and accessibility for all populations. In addition, leaders will continue to focus on issues related to the delivery of services and identification for areas of improvement. Finally, training the future workforce,

decreasing barriers and stress, and increasing diversity will be important issues during the next 10 years. It is only with the consolidated efforts of our community of providers, families, patients, and all advocates that we will make an impact.

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### Disclosures

None.

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