





# ACHA's Vision 2020

Recommendations from Phase I  
From the Vision 2020 Steering Committee

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And the Working Groups on:

-  Accreditation
-  Regional Care Planning
-  Workforce Planning
-  Business Model Development



## **INTRODUCTION AND BACKGROUND**

In December 2008 the Adult Congenital Heart Association (ACHA) established a new initiative, ACHA Vision 2020. ACHA Vision 2020 is an initiative designed to accelerate the development of adult congenital heart care in the United States. The vision for 2020 is that ACHD is an established field that delivers quality lifelong care for adults in the United States. In so doing, the aim is to prevent premature death and disability and prolong health and well-being for congenital heart patients nationwide.

Over the past year, ACHA established four working groups charged with conducting research on what needs to be done in the field of American ACHD care over the next 10 years to meet the vision. The outcome of each workgroup was to provide initial recommendations to the V2020 Steering Committee and the ACHA Board of Directors on how to develop an approach based on their findings and how to accelerate progress in the identified areas. These working groups have brought together national leaders in congenital heart disease to address major existing barriers to providing quality care for the adult congenital population in the United States.

By 2020, the goal is that upon turning eighteen every complex CHD survivor will have access to life-long ACHD care which is:

- High-Quality
- Age-appropriate
- Research- Based
- Coordinated and integrated
- Available in all regions of the country.

This paper presents the recommendations from Phase I of the V2020 initiative.

### ***The Need***

New technologies and medical advances have changed the life expectancy of children born with CHD, enabling the vast majority to survive into adulthood. Over the last 25 years advances in treatment have enabled half a million U.S. children with complex heart defects to survive into adulthood. About 35,000 infants (1 out of every 125) are born with heart defects each year in the United States<sup>1</sup>. Heart defects are among the most common birth defects and are the leading cause of birth defect-related deaths<sup>2</sup>. However, advances in diagnosis and surgical treatment have led to dramatic increases in survival for children with serious heart defects. In the United

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<sup>1</sup> National Heart, Lung and Blood Institute. Congenital Heart Defects. December 2007.

<sup>2</sup> Congenital Cardiovascular Defects: Current Knowledge: A Scientific Statement From the American Heart Association Council on Cardiovascular Disease in the Young. *Circulation*, volume 115, June 12, 2007, pages 2995-3014.

States today, about 1.4 million children and adults live with congenital heart defects (CHD)<sup>3</sup>. Almost all are able to lead active, productive lives. These facts create new demands on the organization for different approaches to building awareness, conducting research, and setting standards of quality for lifelong continuous care.

The conventional approaches to medical care for adults living with CHD and traditional frameworks for collaboration among pediatric and adult cardiologists and between patients and the medical community are increasingly challenged by a rapidly changing scientific, social, and economic environment, and the rapid entry of new actors, technologies, and institutions. For barriers to patient empowerment to be removed and enablers to be established in their place, a vast web of individuals, medical facilities, leaders in the field and their associations must unite to enact real quality metrics and policy measures which bridge social capital and generate professional competence.

### ***The Working Groups***

The first working groups established were predicated on four fundamental principles:

- Quality care should be consistent and definable within and across institutions and there should be a mechanism to communicate to the consumer which institutions meet the quality standards.
- Care for adults with CHD should be age appropriate, comprehensive and integrated.
- The workforce required to meet the needs of adults with CHD should be appropriately trained in the field and to ensure quality their numbers should be adequate to address the growing need.
- Centers to treat ACHD should be able to generate revenue in ways that maintain quality care and provide a viable business model for the larger institution.

To be forward thinking around these four principles, four initial working groups were established to develop the recommendations contained in this document. The Working Groups and their charters are:

- **Program Accreditation.** Establish standards and metrics to create a credentialing system for ACHD programs.
- **Regional Care Planning.** Establish care networks that facilitate collaboration and integration of service delivery.
- **Workforce Planning.** Identify strategies to rapidly expand the workforce of trained ACHD care providers.
- **Business Model Development.** Develop successful business models to promote the development of ACHD care within the current reimbursement system.

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<sup>3</sup> Pierpont, M.E., et al. Genetic Basis for Congenital Heart Defects: Current Knowledge: A Scientific Statement From the American Heart Association Congenital Cardiac Defects Committee, Council on Cardiovascular Disease in the Young. *Circulation*, volume 115, June 12, 2007, pages 3015-3038.

## **RECOMMENDATIONS**

The recommendations from each working group follow. Each working group has provided recommendations for what ACHA should do to move the field toward the specific vision within each area. The recommendations include specific actions, leverage points, and strategic partnerships that should be undertaken to catalyze change in the specific area with ACHA acting as the catalyst.

Together these recommendations define an approach to ACHD care that is regional utilizing a business model that is sustainable and profitable with the right workforce to deliver quality care and an accreditation system that certifies a quality delivery system.

## **Recommendation for a Framework for Accreditation of Adult Congenital Heart Programs**

### ***Vision and Introduction***

ACHA is establishing an accreditation process that defines quality measures and an approach to continuous quality improvement meant to foster creation of high quality ACHD programs. The outcome of being accredited by ACHA is to ensure that patients have a mechanism to identify a quality ACHD health delivery system and to provide programs with objective indicators of organizational quality toward which to strive.

Certification and accreditation are different. Individuals become certified; organizations, institutions, and programs attain accreditation. Both processes can be viewed as being indicative of the quality of services that are being offered. Certification provides the mechanism for an individual to demonstrate that he or she has attained a level of competence in a particular area. Attaining a specific certification credential usually requires satisfactorily completing oral tests, written test(s), and/or hands-on practical exercises. Accreditation is a mechanism for an institution to demonstrate that its quality assurance system and its practices are able to generate valid results. This is accomplished when external assessors review all of the institutions processes and systems as part of an organizational assessment to determine compliance with established national and international standards and criteria. Whenever practical and applicable, the combination of certification(s) and accreditation complement each other in the attainment of quality.

The accreditation approach outlined below positions ACHA as the accrediting body as well as a partner with the applying institution or program. Why partner with ACHA? When partnering with ACHA, programs begin a journey towards quality, patient safety, and organizational improvement. ACHA's accreditation program provides ACHD programs with a self assessment process and an outside evaluation based on Malcolm Baldrige quality standards and the Health Care Criteria for Performance Excellence, the universally accepted standard for a quality management system in the United States.

### ***Recommended Framework***

***What is being recognized through accreditation?*** That an adult congenital heart program has processes (related to organizational structure, technical processes and interpersonal processes), and systems in place to ensure sustainability and durability of those processes that impact the quality of adult congenital heart care. In general, what is being recognized is how the quality of the process by which adult congenital heart care is delivered impacts the ability to improve health.

***How?*** ACHA utilizes an established set of organizational standards and indicators, adapted for use in adult congenital heart practice. Use of an identified set of Quality Standards based upon the Malcolm Baldrige<sup>4</sup> National Quality Standards. The standards are designed to evaluate both organizational and programmatic effectiveness.

***Approach:*** To establish a set of Quality Standards and indicators that is used to assess an

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<sup>4</sup> The Malcolm Baldrige National Quality Improvement Act of 1987 - Public Law 100-107

organization's effectiveness and the effectiveness of the ACHD program's key elements. The process of external quality review used to scrutinize ACHD programs for quality assurance and quality improvement. Success results in an accredited institution and/or program.

### **Establish a Two-Step Process**

*Step 1: Self-Assessment.* Institutions/programs go thru a self assessment process to conduct a gap analysis (current state against the standards and indicators) and to identify opportunities for improvement. The self-evaluation is meant to assist organizations in understanding how to meet or exceed the Quality Standards. Self-assessment strategies represent a common category of approaches used in the U.S. to document quality of products, institutions and programs. While self-assessment does not replace other forms of documenting quality such as the use of control group evaluations, these processes have roots in both the public and private sectors. The national emphasis on quality standards and excellence has been embraced by nearly every field including business, health care, and education.

Common uses of self-assessment include its utility to:

- Recognize institutions.
- Recognize programs.
- Recognize products and services.
- Promote quality.
- Provide national affiliation and recognition.
- Promote programs supported by state/federal government

Specifically, the purpose of this self evaluation is to:

- Prioritize areas for improvement within the organization
- Identify the impacts of the system on the quality of the processes and outcomes,
- Develop a shared Action Plan for improvements
- Prepare to submit an application for accreditation from ACHA

*Step 2: Submit Application.* An organization/program submits an application for accreditation to ACHA that requires descriptions of how processes, systems and practices are in place to meet the standards' indicators. ACHA reviewers/assessors review the application and make site visits as required. Whether accredited or not, ACHA issues a technical assistance report which identifies strengths and areas for growth and quality improvements.

### **Key Features**

- Programs either meet the standards or they do not. They do not have to meet all the criteria at 100%. A rating scale is established with a 'cut point' – below it the program is not accredited and above it the program is accredited.
- Programs would be accredited for a period of X number of years, and then have to resubmit.
- From a quality improvement perspective, the gap analysis process is viewed as valuable to the institution, with or without accreditation.
- Accreditation means that the institution/program has been recognized by ACHA as having quality process by which health care is delivered. It does not necessarily mean the

accredited program is ‘better’ than the one that did not apply; rather it means that the program took the time and expended the resources to have an outside review of its processes and practices and has been awarded such recognition.

***Some Initial Issues for Consideration:***

- ✓ Given that accreditation is the establishment of the status, legitimacy or appropriateness of an institution’s quality, does ACHA have the standing to be the accrediting body?
- ✓ Should there be such a thing as ‘provisional certification’, i.e., the program was close, however a few key (pre defined) criteria were missed – does the institution get a chance to bring those things into alignment and then resubmit a limited application without having to go thru the entire process if they do it within 3 (as example) months?
- ✓ Are the indicators broad enough and inclusive enough to be used for both in-patient and out-patient programs?
- ✓ How to establish a brand and a value proposition for the recognition that makes it worthwhile to obtain. Making it a commodity with patients so they ask – Have you been accredited by ACHA?
- ✓ How to ensure an unbiased review process that establishes an exemplar and sticks to it.

***Recommendation: First Draft of Indicators for Each Standard***

**I. LEADERSHIP**

Leadership refers to how the organization’s senior leaders’ and how their personal actions guide and sustain the organization. The organization’s governance system and how the organization fulfills its legal, ethical, and societal responsibilities and supports its key communities are part of the definition of an overall leadership system.

- **Indicator:** The organization has a process for setting organizational vision and values.  
(*Application Question:* How do senior leaders set organizational vision and values?)
- **Indicator:** The organization has created an environment to sustain the ACHD program.  
(*Application Question:* How do senior leaders create a sustainable organization including a process for succession planning; how do they create an environment focused on organizational performance improvement?)
- **Indicator:** Demonstrated commitment to patient safety.  
(*Application Question:* How do senior leaders create and promote a culture of patient safety?)
- **Indicator:** Collaboration with other centers.  
(*Application Question:* How do senior leaders promote a culture of collaboration with other centers for research, development of outcomes-based measures of quality, and referral?)
- **Indicator:** Leaders are learners and develop institutional knowledge.  
(*Application Question:* How do leaders participate in and contribute to professional education programs within the institution as well as in other professional capacities?)
- **Indicator:** Leaders recognize and support the ACHD program.  
(*Application Question:* Describe how the ACHD program is supported by the leadership as a center of ACHD care and research?)

## 2. STRATEGIC PLANNING

How the organization sets strategic directions and determines key action plans. Also, how the plans are translated into an effective performance management system. How does the organization deploy strategic objectives and action plans and how these are changed if circumstances require.

- **Indicator:** The organization has a strategic planning process, including demonstrated strategic support for ACHD programs.  
(*Application Question:* How does the organization conduct its strategic planning? Include how ACHD programs are included in the planning process.)  
(*Application Question:* How do your strategic objectives address your strategic challenges?)
- **Indicator:** There are long and short term goals and time horizons.  
(*Application Question:* What are the key strategic goals and objectives and the timetable for accomplishing them, including ACHD program goals? Include short and long term program goals.)
- **Indicator:** Measurement of the outcomes of organizational strategy.  
(*Application Question:* What are your key performance measures for tracking the achievement and effectiveness of the action plans that support your strategic goals?)
- **Indicator:** Demonstrated strategic partnerships and alliances.  
(*Application Question:* Describe strategic partnerships designed to enhance a partnership model of care. How does the institution and the ACHD program collaborate with regional providers to enhance access for patients?)

## 3. CUSTOMER AND MARKET FOCUS

How the organization engages its patients and stakeholders for long-term marketplace success. This engagement strategy includes how the organization builds a patient- and stakeholder-focused culture. Also how your organization listens to the voice of its customers (patients and stakeholders) and uses this information to improve and identify opportunities for innovation.

- **Indicator:** The program has a customer satisfaction data collection and analysis system.  
(*Application Question:* How do you collect patient and stakeholder feedback to assess their satisfaction and act on it? How do you manage patient complaints?)  
(*Application Question:* How do you identify and innovate health care services offerings to meet the requirements and exceed the expectations of your patients, stakeholder groups and market segments?)  
(*Application Question:* How do you create an organizational culture that ensures a consistently positive patient experience and fosters patient engagement?)  
(*Application Question:* How do you determine patient and stakeholder satisfaction and engagement?)
- **Indicator:** Access to ACHD services is facilitated.  
(*Application Question:* How do you determine your key mechanisms to support use of your health care services and enable patients and stakeholders to seek information and otherwise utilize you services? Include how your program fosters provision of ACHD care to areas remote from the ACHD center through CME, outreach clinics, online resources for referring cardiologists.)
- **Indicator:** Demonstrated collaboration to ensure quality patient care.  
(*Application Question:* How do you collaborate with pediatric cardiology practices to foster continued transition to ACHD programs?)  
(*Application Question:* Describe how the program maintains communication with referring physicians.)  
(*Application Question:* How do you collaborate with other ACHD programs to ensure migratory patients are able to get care when moving out of the area?)

*(Application Question:* Describe how forums for multidisciplinary case reviews are supported and facilitated by the institution.)

#### 4. MEASUREMENT, ANALYSIS, AND KNOWLEDGE MANAGEMENT

How the organization selects, gathers, analyzes, manages, and improves its data, information, and knowledge assets and how information technology is managed. How the organization reviews and uses reviews to improve its performance.

- **Indicator:** Developed data collection and analysis systems with consistent use.  
*(Application Question:* How do you select, collect, align and integrate data and information for tracking daily operations and for tracking overall organizational performance? Include mechanisms to track volume, demographics, and specific outcomes.)  
*(Application Question:* How do you ensure the following properties of your organizational data, information, and knowledge: accuracy, integrity and reliability, timeliness, and security and confidentiality?)  
*(Application Question:* How do you ensure that hardware and software are reliable, secure and user-friendly?)
- **Indicator:** Demonstrated referral process.  
*(Application Question:* Describe your referral process to other ACHD programs for those services, such as heart transplantation, if it is not available "in house".)  
*(Application Question:* Describe how the ACHD program develops regional referral links and linkages to other providers for ACHD patients e.g. high risk OB, general surgery, cardiac anesthesia, gastroenterology, ENT)
- **Indicator:** Demonstrated system to manage knowledge.  
*(Application Question:* Describe the knowledge management system<sup>5</sup> used to systemically transfer knowledge.)  
*(Application Question:* Describe how you translate new research into clinical practice.)  
*(Application Question:* Describe the methods used to improve conforming to or responding to published standards and guidelines.)  
*(Application Question:* How does your program implement established guidelines for treatment of CHD and CAD prevention strategies?)
- **Indicator:** Continuous quality improvement practices are in place.  
*(Application Question:* Describe CQI processes to ensure all imaging is high quality.)

#### 5. WORKFORCE FOCUS

How the organization engages, manages, and develops the workforce to utilize its full potential in alignment with the organization's overall mission, strategy, and action plans. The institutions ability to assess workforce capability and capacity needs and to build a workforce environment conducive to high performance.

- **Indicator:** The organization has a focus on learning and development.  
*(Application Question:* How does your learning and developments system address the following factors for your workforce and your leaders:
  - Your organizations core competencies
  - Licensure and re-credentialing requirements
  - Organizational performance improvement and innovation
  - Ethical health care and ethical business practices
  - The breadth of development opportunities, including education, training, coaching,

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<sup>5</sup> An organizational process for converting information into knowledge and making that knowledge accessible to those within the organization.

mentoring and other experiences as appropriate, transfer of knowledge from departing or retiring workers.

*(Application Question:* How do you assess your workforce capability and capacity needs, including skills, competencies, and staffing levels? Include descriptions of the expertise and experience needed of team members and multispecialty consultants.)

*(Application Question:* Describe how the program participates in medical student, resident and fellow education to ensure trainees are aware of ACHD as a both a career option and as a referral need.)

*(Application Question:* Describe how non-ACHD providers are incorporated into ACHD care with continued education for non-ACHD providers on relevant ACHD topics.)

- **Indicator:** Clinical environment appropriate for adults.

*(Application Question:* Describe how you achieve an appropriate clinical environment for care of the adult patient.)

## 6. PROCESS MANAGEMENT

The key aspects of process management include how the organization designs its work systems how it designs, manages, and improves its key processes for implementing those work systems to deliver value to patients and stakeholders and achieve organizational success and sustainability.

- **Indicator:** The organization understands key work processes and how to improve them.  
*(Application Question:* What are your organizations key work processes? How do these processes contribute to delivering patient and stakeholder value, profitability or financial return, organizational success and sustainability?)

*(Application Question:* How do you address and consider each patients expectations, how are services delivery processes explained to set realistic patient expectations. How are patient decision making and patient preferences factored into the delivery of health care services?)

*(Application Question:* How do you improve your work processes to achieve better performance, to reduce variability, to improve services and outcomes, to keep processes current with health care service business needs and directions?)

- **Indicator:** Demonstrated case management process.

*(Application Question:* Describe how often you conduct case conferences for management and planning. Include the process for multidisciplinary case reviews.)

- **Indicator:** Demonstrated referral process.

*(Application Question:* Describe the flow of patients into ACHD care including transition program, criteria for initial assessment, and referrals for procedures.)

*(Application Question:* Describe the referral process for non-ACHD problems.)

## 7. RESULTS

This includes the organization's performance and improvement in all key areas—health care outcomes, patient-focused outcomes, financial and market outcomes, workforce-focused outcomes, process effectiveness outcomes, and leadership outcomes. Performance levels are examined relative to those of competitors and other organizations with similar health care service offerings.

- **Indicator:** Demonstrated systematic tracking of levels and trends for various outcome measures.

*(Application Question:* What are your current levels and trends in key measures of health care outcomes, patient safety and patients' functional status? What are the outcomes for all ACHD related procedures? What are the outcomes for common non-ACHD issues such as pregnancy and non-cardiac surgery? How do these results compare with the performance of your competitors with similar health care service offerings?)

*(Application Question:* What are your current levels and trends in key measures of patient and stakeholder satisfaction and dissatisfaction?)

**(Application Question:** What are your current levels and trends in key measures of financial performance, including aggregate measures of financial return, financial viability or budgetary performance as appropriate?)

**(Application Question:** How often do you review morbidity and mortality rates? What are your current trends?)

**(Application Question:** Describe how the ACHD program regularly reviews outcomes of surgical or interventional procedures. Describe the ACHD program's quality measures for care of adults on inpatient and outpatient basis and how they are routinely monitored and meet national standards.)

- **Indicator:** Focus on prevention.

**(Application Question:** How does the program address preventative issues, per accepted guidelines, including obesity, exercise, cholesterol, and other standard CAD prevention/treatment measures.)

## **Recommendation for the Approach to Regional Care Planning**

### ***Vision***

The vision of the Regional Care Planning Group is to create collaborative regional networks of high-quality ACHD services to enable patients to reach recommended care regardless of location. Central to this vision are the following core principles:

- ACHA's role is to create a frame in which all parties are called upon to put the good of the patient ahead of any potentially competing priorities.
- Each region faces its own unique challenges which will be best solved by regionally-defined and regionally-implemented solutions.
- Only by engaging in regional dialogue and by establishing a collaborative approach will existing barriers to ACHD care be overcome.
- Consumer demand for quality and the patient/family voice demanding quality will be central in promoting change.
- Promoting better regionalized ACHD care access will require a full partnership between ACHD and pediatric cardiology services/providers in all regions.
- ACHA's regional approach will build directly on ACHA's accreditation efforts, and all centers which meet ACHA-defined accreditation standards will be considered ACHD programs. No attempt will be made to limit or exclude qualifying ACHD programs based on geography.

ACHA's role is to help develop the assessment, planning, education, communication, and oversight tools necessary to develop a regionalized approach. In the end each region should have:

- An inventory of all CHD resources available in the region and a description of the "as-is" referral relationships and care patterns
- A regional analysis of strengths, weaknesses, opportunities and threats (SWOT) to define existing needs and barriers
- A plan to improve regional ACHD care networking in order to improve access to care
- A defined ACHA regional leadership team able to oversee and assist in the implementation of the regional care plan objectives.
- Mechanisms to promote regional collaboration, such as regional CME conferences, regional case sharing, and the use of teleconferencing.
- An ACHA chapter system which parallels the defined regional structure.

### ***Recommendations***

In order to make progress in reaching these objectives, the group recommends that ACHA take the following actions:

#### **Phase I – Organization and Inventory**

- Divide the country into 6 regions to facilitate planning and communication, as follows [Northeast, Northwest, Southeast, Southwest, Great Lakes, and Central] with the

expectation that as the groups describe the existing referral patterns they will adjust regional borders as necessary

- Define an initial ACHA leadership team to oversee a regional inventory
- Each team will be charged with
  - Creating a full inventory of all CHD resources (pediatric and adult) within the region
  - Asking all major pediatric centers their planned provision of ACHD care for their patients
  - Asking all major adult cardiology centers their planned provision of ACHD care for their patients
  - Describing the “as-is” state of referral patterns, care, and future plans within the region

## Phase II - Definition of Plan and Structure

- ACHA should convene regional meetings to share the “As-Is” descriptions
- Each region should collectively define leadership to engage in a SWOT analysis based on as-is state, using existing ACHD care guidelines as the standard as to what kinds of specialized OR, ER, EP, imaging, anesthesia, ob-gyn, outpatient, and inpatient resources should be available.
- Specific actions to achieve the desired end-state will be defined
- A leadership team capable of promoting change in the region will be identified, with appropriate representation from both pediatric and adult CHD providers, as well as from appropriate institutions, clinical cardiology, insurance, regional government(s), and consumers
- Concrete timelines and milestones will be identified for promoting change.
- Each region should identify strategies to
  - Develop and implement strategies to reduce the loss-to-care of patients with complex CHD
  - Encourage transition to ACHD care within their region
  - Promote awareness of and compliance with ACHD care guidelines within their region
    - By providers
    - By consumers
  - Address existing insurance barriers within their region
  - Promote the regional improvement of ACHD care through medical education, collaboration, and case-sharing

In addition, ACHA should pursue the following strategies at the national level

- Regularly convene regional leadership to a national summit to share strategies and approaches
- Organize and coordinate regional conferences and CME
- Create centralized electronic resources to promote regional collaboration and education

- Partner with appropriate pediatric groups to create a centralized listing of pediatric congenital resources to augment the ACHD program directory
- Make available to patients, families, and providers accurate and up-to-date web-based information about how to access ACHD care in their region
- Work with each region to identify potential regional sources of funding for new programs targeted to better serve ACHD patients and care providers in that region
- Secure national funding to create one or two pilot programs to develop regional ACHD care networks selected by ACHA national.
- Support the development of a regionalized chapter system to support future regionalized fundraising and advocacy by consumers as well as providers.
- Partner with ACC at the chapter level to support multi-state educational and awareness-building campaigns
- Create new mechanisms for consumer feedback to report not only on specific ACHD programs but also the efficacy of regional systems, and through which consumers can report problems accessing specific types of care within a specific region.

## **Recommendation for Workforce Planning**

### ***Findings:***

Since 50-90% of the ACHD population is not receiving regular care by an ACHD cardiologist, an estimated doubling of the present number of FTEs of ACHD cardiologists would be required to serve this population and a slightly greater number of FTEs of mid-level providers would be needed to provide appropriate patient navigation and prevent drop-out of young adults. (Since many providers combine ACHD care with other activities, the number of FTE's does not equate directly with the number of providers). Specific and extensive data prepared by Dr. Hoffman, is presented in the attachment.

Inadequate funding for providers and institutions for ACHD care is a significant limitation to assuring an adequate workforce required to provide access to care for all patients with ACHD.

The educational curriculum of Level 1 cardiologists should be enhanced to include the appropriate ACHD content.

A survey of 15 ACHD centers around the country provided estimates that a team of one full time equivalent (FTE) ACHD physician and one ACHD advanced care provider (nurse practitioner or physician assistant) could safely care for an average of 750 patients (range: 250 to 1,500 patients). For a team of 2 physicians and 2 advanced practice providers, the estimated workload increased to approximately 1800 patients (range: 750-4,000). Given the large variation in responses, it is clear that further refinement of appropriate provider to patient ratios is needed. However, the survey reinforces the contention that our current work force is far from adequate to care for the current estimated ACHD patients, let alone serve the continually expanding population.

The results of the survey also support the notion that work within a team-based medical home will provide more efficient and higher quality care for this population. Experience with the organization of this team will impact the number of required Level 3 ACHD providers in the future.

### ***Recommendations:***

ACHA should work with the appropriate partners (which might include the ACHD Workgroup of the ACC and others) to develop a white paper on the present and projected workforce needs. The paper should incorporate as much data as is currently available, including data provided by Dr. Hoffman. The paper needs to address training needs from a broad perspective, inclusive of not only physicians, but also nurses, sonographers and other key players.

This paper should include the other workgroup findings to provide a document for presentation to federal and state funding agencies, AHRQ, IOM and Congress. This document should explicitly define the funding issues for training of ACHD specialists and maintenance of the

ACHD team at the regional centers as well as the appropriate reimbursement for all ACHD services.

Formal representation between ACHA MAB and ACHD Workgroup of ACC should be initiated in order to coordinate and reinforce these activities.

Continue and expand lobbying efforts and partnership with the National Heart Lung and Blood Institute (NHLBI) to increase funding for training.

**Timeline:**

Representatives of ACHA MAB and ACC ACHD Workgroup should convene at the spring 2010 Vision 2020 meeting to determine the structure of bilateral representation and to designate a writing group for the position paper.

## **Recommendation from the Business Model Working Group**

### ***Vision***

The vision of the *Business Model Working Group* is to provide information and a process for US ACHD programs to develop and project financial security and productivity attractive to both hospital administrators and ACHD health care professionals. The Business Model includes:

- Background information regarding insurance payor mix
- A prospective clinical model to predict ACHD program revenue and growth
  - a. Utilizes published ACHD guidelines to predict testing and follow up care.
  - b. Projected clinic visits, diagnostic testing, therapeutic interventions and follow up care are modeled in a disease specific pathway to predict revenue.
  - c. Projected revenue is utilized to allocate necessary resources
- An ACHD coding manual for inpatient care, out patient care and cardiovascular procedures.
- Administrative strategies to demonstrate productivity and downstream revenue
- Ongoing administrative assistance from the National Network of ACHD Program Administrators.

### ***Recommendations***

The working group's recommendation(s) for what ACHA should do to move the field toward the particular vision. Specific actions, leverage points, strategic partnerships, etc, that should be undertaken to catalyze change in the specific area with ACHA acting as the catalyst.

- Support Network of ACHD Administrators (see above) by acting as a liaison between ACHD programs in this network.
- Provide pocket coding manual for ACHD health professionals
- Help produce (formatted into a document) and provide The ACHD Business Model
- Support site visits by the ACHD Business Model Team to assist start-up program development.
- Develop other publications as defined.

## **NEXT STEPS**

It is the intention of the Vision 2020 Steering Committee to present these initial recommendations to a broader network of pediatric and adult cardiologists and other members of the medical community in April 2010 for feedback and direction. As ACHA enters year two of the ten year plan to ensure ACHD as an established field that delivers quality lifelong care for adults in the United States, we embark on a comprehensive approach to implement the strategies outlined in the recommendations presented.