Health Reform

HOD Executive Summary

House of Delegates August 2009

With national policy makers focusing on health care reform and the surfacing importance of the patient centered medical home model (PCMH), the HLT determined that the role of ADA members within future models of care will need to be addressed by the profession so that in the next 3-5 years we are positioned to be the providers of food and nutrition services.

During the Fall 2009 House of Delegates Meeting in Denver, CO, participants will discuss the following:

- **Discussion Question:** What needs to happen to engage ADA members as an integral part of future health care models?
- **Expected Outcomes:** Attendees will:
  - Collectively better understand what is going on at the state level.
  - Better understand ADA’s legislative efforts.
  - Link state level activities with national activities.
  - Develop strategies that can be utilized in their state or area of practice.

The two ADA documents, “Health Care Reform” and “Patient-Centered Medical Home Strategic Plan” are included as the background reading for this dialogue. “Health Care Reform” was released in December 2008 as a result of the American Dietetic Association’s task group that was appointed to develop the Association’s recommendations regarding health care reform. In March 2009, the Medical Home Workgroup consisting of ADA staff was charged to gather and assess information related to RDs’ current involvement in this model of care.

“Health Care Reform” sets tenets by which ADA will analyze and critique national health reform proposals. Efforts will focus on preventive and interventional health promotion and care, highlighting the role of the registered dietitian in maintaining health and wellness, disease prevention, and chronic care management throughout the continuum of life – from prenatal to end-of-life care.

These tenets are as follows:
1. The health of all Americans should improve as a result of our health policy choices. Sufficient resources must be made available to ensure optimal health.
2. Access to quality health care is a right that must be extended to all Americans.
3. Nutrition services, from prenatal through end of life, are an essential component of comprehensive health care.
4. Stable, sufficient, and reliable funding is necessary for our health care system to provide everyone access to a core package of benefits.
5. Health care must be patient-centered.

Based on the five aforementioned tenets, the Health Care Reform Task Group recommended that the following policy positions be adopted by ADA as essential to any national health care reform package:
1. The primary focus of any health care initiatives must be to improve the health status of Americans. The vital and unique role that nutrition plays in improving and maintaining an individual’s health as well as the health of all Americans should be explicit in US health policy.
2. Every American has a fundamental right to the best quality of health care available. This right includes access to: Healthy food and qualified health professionals, including registered dietitians.
3. Nutrition services are critical to comprehensive health care delivery systems. Health maintenance, wellness, disease prevention and early detection, delay in disease progression, and intervention in chronic care management are necessary components of a comprehensive health policy.
4. The nation has to address the increased costs of health care and act now to:
   - Expand coverage of nutrition services to a broader range of services where MNT will improve health outcomes.
   - Improve the coordination of health care and disease management.
   - Include nutrition care provided by registered dietitians in team based programs, and cover preventive and interventional nutrition services by individual RD providers.
   - Improve and expand health information technologies, and fully integrate nutrition status data into both medical records and personal health record systems. Health information technologies should be geared toward improving health and health care quality, thereby reducing unnecessary expenses, and inefficiencies in the delivery of care.
   - Support a viable economic infrastructure that patients can rely on through sound, sustainable funding.
   - Fair market value is the appropriate standard for nutrition services reimbursement.

5. Nutrition education, nutrition assessment, nutrition counseling, and nutrition interventions are examples of the unique knowledge, training, and skills RDs possess and will prove to provide unmatched value to the patient.

Congress is interested in increasing preventive services. Many ideas rely on the recommendations of the United States Preventive Services Task Force. The USPSTF recommends intensive behavioral dietary counseling for adult patients with hyperlipidemia and other known risk factors for cardiovascular and diet related chronic disease. Intensive counseling can be delivered by primary care clinicians or by referral to other specialists, such as registered dietitians. ADA is committed to working with Congress in drafting a bill that puts the proper emphasis on prevention and disease management while making nutrition a key element of these services.

The PCMH Workgroup relied on the following definition from the National Committee for Quality Assurance (NCQA): “The PCMH is a model for care provided by physician practices that seeks to strengthen the physician-patient relationship by replacing episodic care based on illnesses and patient complaints with coordinated care and a long-term healing relationship. Each patient has an ongoing relationship with a personal physician who leads a team that takes collective responsibility for patient care. The physician-led care team is responsible for providing all the patient’s health care needs and, when needed, arranges for appropriate care with other qualified physicians”.

Patient-Centered Medical Home Strategic Plan recommended the following goals with strategies further outlined in their May 2009 report:

1. Goal #1: Current and future RDs are empowered to advocate for inclusion in the patient centered PCMH and other health care models as the preferred provider for food and nutrition services.
2. Goal #2: The PCMH providers value and choose RDs as preferred providers for food and nutrition services.

ADA’s infrastructure to support our public policy mission through grassroots involvement includes every member. Together we can make a difference. Key persons in grassroots work include: Public Policy Coordinators (national issues), State Policy Representatives (state issues), Public Policy Panels (Affiliate Presidents, PPCs, SPRs and others), DPG Legislative Chairs or Public Policy Liaisons, ADAPAC (Political Action Committee), Legislative and Public Policy Committee (national committee), the Policy Initiatives and Advocacy Team staff, and communications (On the Pulse, Journal of the American Dietetic Association, and ADA Web site).

In preparation for the House of Delegates dialogue session on health reform, delegates will be determining what is going on in the states in regards to the role of the RD in health reform? For example, are RDs covered in Medicaid plan; how are ADA members in the state involved in preparing for health reform?

Delegates will be discussing these questions with affiliate Public Policy Coordinators (www.eatright.org/ada/files/PPC_09-10.pdf) and Dietetic Practice Groups Legislative/Public Policy Chairs (contact DPG via www.eatright.org/leaderdirectory). Delegate contact information can be obtained from www.eatright.org/leaderdirectory.

To obtain the full backgrounder “Health Reform”, visit www.eatright.org/HODBackgroundersFall2009.
Health Reform

HOD Backgrounder

House of Delegates

August 2009

With national policy makers focusing on health care reform and the surfacing importance of the patient centered medical home model (PCMH), the HLT determined that the role of ADA members within future models of care will need to be addressed by the profession so that in the next 3-5 years we are positioned to be the providers of food and nutrition services.

Discussion Question: What needs to happen to engage ADA members as an integral part of future health care models?

Expected Outcomes:
Attendees will:
- Collectively better understand what is going on at the state level.
- Better understand ADA’s legislative efforts.
- Link state level activities with national activities.
- Develop strategies that can be utilized in their state or area of practice.

Knowledge-based Strategic Governance is a mechanism for consultative leadership. It recognizes that “strategy” is the necessary and appropriate link in the Board’s role to govern the profession, the House’s role to govern the profession and the staff’s role to manage implementation. The two ADA documents, “Health Care Reform” and “Patient-Centered Medical Home Strategic Plan”, need to be read prior to any discussion of the role of ADA members in health reform are provided.

“Health Care Reform” was released in December 2008 as a result of the American Dietetic Association’s task group that was appointed to develop the Association’s recommendations regarding health care reform.

In March 2009, Medical Home Workgroup consisting of ADA staff was charged to gather and assess information related to RDs’ current involvement in this model of care. Their charge was to develop for the House of Delegates Leadership Team and the ADA Board of Directors a strategic plan for engaging members in this model. This Workgroup released its report in May 2009.

Lastly, we are providing you with a pertinent article that was published in the Pediatric Nutrition Practice Group’s newsletter, Building Blocks, titled “Medical Home: Focus On Nutrition Services in the Community” by Kate Orville, MPH, Betty Lucas, MPH, RD, CD, Katherine TeKolste, MD.

ADA’s infrastructure to support our public policy mission through grassroots involvement includes every member. Together we can make a difference. Key persons in grassroots work include:

- **Public Policy Coordinators**, who connect grassroots advocates to the larger program of ADA advocacy. PPCs encourage grassroots training and participation in ADA and affiliate initiatives, follow through on ADA Action Alerts and help build and sustain grassroots networks. PPCs are the primary contacts for Public Policy Workshop advocacy in the state. They are familiar with ADA’s public policy processes and stances.
• **State Policy Representatives**, who manage state and local advocacy agendas and tactics. SPRs identify state legislators and agency officials in positions to affect dietitians’ professional standing as well as significant food, nutrition and health matters. SPRs coordinate the affiliates’ annual meeting in the governor’s office and organize the state legislative day activities.

• **Public Policy Panels**, consisting of Affiliate Presidents, PPCs, SPRs and others within the affiliate who prioritize and oversee the affiliate’s public policy agenda of 3 to 5 issues.

• **ADA’s 28 Dietetic Practice Groups (DPGs)**: Some DPGs have appointed a Legislative Chair or Public Policy Liaison to follow issues relevant to the practice area and mobilize DPG members.

• **ADAPAC**: ADA’s political action committee. ADAPAC collects funds to be donated to political candidates who support ADA’s priorities ([www.adapac.org](http://www.adapac.org)).

• **Legislative and Public Policy Committee**: The Legislative and Public Policy Committee (LPPC) guides the establishment of the ADA’s public policy work including (but not limited to) activities related to national and state public policy, legislative, and regulatory issues.

• **The Policy Initiatives and Advocacy Team staff**: This group of ADA staff members located in the Washington work on food nutrition and health issues to influence policy at the federal, state and local levels. Dedicated to identifying issues and advocating for the profession, also manages ADAPAC and provide support and training for the Dietetic Practice Groups and ADA affiliates nationwide.

• **Communication**: Several resources are provided by ADA for grassroots activist members: (1) the weekly e-newsletter, *On the Pulse*, and (2) the *Journal of the American Dietetic Association*. Webinars for leadership training and issue updates occur throughout the year. Affiliate conference calls held by the Policy Initiatives and Advocacy Staff are held frequently to coordinate ADAPAC efforts. In addition, the ADA Web site, [www.eatright.org](http://www.eatright.org), makes this important information available online. Member alerts, testimony and position statements are regularly posted on the Web site.

In preparation for the House of Delegates dialogue session on health reform, determine what is going on in your state in regards to the role of the RD in health reform? For example, in your state, are RDs covered in Medicaid plan; how are ADA members in your state involved in preparing for health reform?

Contact your affiliate president or DPG chair to determine your affiliate Legislative Chair or a Dietetic Practice Groups Legislative/Public Policy Chair. Contact information can be obtained from [www.eatright.org/leaderdirectory](http://www.eatright.org/leaderdirectory). The list of Public Policy Coordinators for the 2009-10 program year can also be found at [www.eatright.org/ada/files/PPC_09-10.pdf](http://www.eatright.org/ada/files/PPC_09-10.pdf).
america is facing a health crisis. For decades the Congress and Presidents alike have struggled with how to reform health care. On November 19, 1945, only 7 months into his presidency, Harry S. Truman gave a speech to the United States Congress proposing a new national health care program. In his speech, Truman argued that the federal government should play a role in health care, saying "The health of American children, like their education, should be recognized as a definite public responsibility."

Ever since that time, the debate over health care has continued. Even with passage of Medicare and Medicaid in 1965, health care has remained a major issue facing America. Today few would argue that our health care system is functioning well. The issues involved are complex and multifaceted:

- There are 47 million Americans without health care coverage.
- Access to health care is often dependent on the patient’s insurance status and policy.
- The current system of coverage that is provided by employers is not flexible enough to meet peoples’ needs.
- Providing health care insurance to employees is making American companies non-competitive.
- Both Medicare and Medicaid are fiscally unsustainable.

Dissatisfaction with the U.S. health care system is prevalent among patients and health care providers alike. In part this is due to the fact that there is not a single system, but a hodgepodge of different health care non-systems acting independently of each other. The primary methods of health care finance—employer-based insurance, means-tested insurance, and Medicare—are deeply and irreparably defective.

The fragmentation of our health care delivery systems often results in frustrating and dangerous patient experiences, in particular for patients receiving care from a variety of health care providers in multiple settings. It also leads to waste and duplication.

Our current health care system is based on crisis-intervention and disease-care with others than providers making medical decisions. The emphasis is not on disease prevention, wellness and healthy lifestyles.

Few issues that will confront the United States will have a larger economic impact than addressing health and the systems that serve it. American health literacy is low and our habits frequently contribute to costly disease and conditions. Although nearly half of the people in the United States suffer from preventable chronic conditions, relatively few resources have been directed to the broad array of potential solutions that influence whether and how individuals choose to achieve and maintain health. Attention to health maintenance and disease prevention not only could save lives, but save money by preventing the onset of chronic conditions or the progression of chronic diseases.
Obesity has become an epidemic, affecting nearly every age group and demographic. Of particular concern is the increased obesity rate among children and the accompanying increase in diseases such as hypertension and type 2 diabetes. Heart disease is the leading cause of death in the U.S. and stroke is the third leading cause. These two cardiovascular diseases account for more than 35% of all deaths in the United States and are among the most widespread and costly health problems facing our nation today, yet they are also among the most preventable.

According to the American Diabetes Association,

*The total annual economic cost of diabetes in 2007 was estimated to be $174 billion. Medical expenditures totaled $116 billion and were comprised of $27 billion for diabetes care, $58 billion for chronic diabetes-related complications, and $31 billion for excess general medical costs. Indirect costs resulting from increased absenteeism, reduced productivity, disease-related unemployment disability, and loss of productive capacity due to early mortality totaled $58 billion. This is an increase of $42 billion since 2002. This 32% increase means the dollar amount has risen over $8 billion more each year.*

Public health strategies and policies that promote healthy living, encourage healthy environments, and promote control of the diet-related chronic diseases/conditions such as obesity, hypertension, high cholesterol, stroke, metabolic syndrome, diabetes, GI/GU cancers are keys to improving the public’s health, saving lives and saving money.

Because Congress must debate and pass legislation focused on health care reform, the American Dietetic Association formed a task group to develop the association’s recommendations.

ADA Health Care Reform Task Group members are:

Lorri Holzberg, MA, RD, CDE (Chair)
Kessey J Kieselhorst, MPA, RD, CDE, LDN
Cecilia Pozo Fileti, MS, RD, FADA
Jane V White, PhD, LDN, RD, FADA
Michael O Fleming, MD, FAAFP
Brenda E Richardson, MA, RD, LD, CD.

ADA staff who participated in task force activities included Stephanie Patrick, Vice President of Policy Initiatives and Advocacy, spatrick@eatright.org and Ron Smith, Director of Government Relations, rsmith@eatright.org.
The U.S. health care system is broken. Current spending in Medicare and Medicaid represents a significant portion of the nation’s federal budget deficit, and according to the Congressional Budget Office, the rate of growth in health care costs is the most important factor influencing the federal government’s long-term fiscal situation. Health care problems extend into the private sector as well, where the cost of providing coverage is largely born by businesses, and represent a significant burden to small and large companies alike. Meanwhile, individual coverage is largely unaffordable and in some cases unavailable due to pre-existing conditions.

As former Majority Leader of the Senate, Tom Daschle says in his book What we can do about the Health Care Crisis “It’s hard to think of another public policy problem that has lingered, mostly unaddressed, for so long.”

Managing a way out of the financially unsustainable situations of Medicaid and Medicare and of private sector systems is made more difficult by:

- Demographic shifts to an aging society who demands more health care spending.
- Patients wanting new medical advancements – devices and technologies -- are extremely expensive.
- Systemic voids in evidence-based knowledge of the effectiveness of medical practices and treatments.

In 2006 ADA published a report entitled “The Profession of Dietetics at a Critical Juncture: A Report on the 2006 Environmental Scan for the American Dietetic Association”. That report concluded in part the following:

*Health care reform and the possibility for a universal health care system may be driven by the need to make the U.S. economy more competitive against the economies of India and China. As a U.S. automaker recently pointed out, the $1,500 in worker health care costs that goes into every car made in the United States is a serious competitive disadvantage. In future, health care reform to take this burden off the backs of employers will gain support from U.S. corporations.*

*The broad social and medical changes that will be needed to cope with the twin epidemics of obesity and diabetes could provide U.S. society with the direction and models needed to reform the whole health care system. Most of these involve prevention.*
Examples are:

- Whole population prevention strategies to encourage healthful lifestyles.
- Effective countering of the social and physical factors in modern life that lead people to be overweight or obese—this could require big changes in society to get people to get more exercise, and provide free or low-cost ways for them to do it.
- Regular screening for diabetes, with preventive strategies that kick in when prediabetes conditions are identified.
- Better chronic disease management, counseling, and self-care with more knowledge and the tools to navigate the health care system.
- Advances in technologies that deliver better information to people and their medical conditions.
- Digitization of medical records, and development of personal electronic medical histories for each consumer.
- Access to health care for all.
- Individualized care based on genetic knowledge.

Even though America spends more than $2 trillion annually on health care -- more than any other nation in the world -- tens of millions of Americans suffer every day from preventable diseases like type 2 diabetes, heart disease, and forms of cancer that deny a patient both quantity and quality of life. The dramatic growth of preventable chronic diseases represents both a challenge and an opportunity for the nation. Without dramatic changes in our health care delivery system, the cost of treating chronic conditions will overwhelm state and federal budgets in the coming years. By improving preventive care and team-based disease management through comprehensive health care reform, we can keep people healthier and spend less money doing so.

To redesign the health care delivery system within the United States to provide targeted, accessible, continuous and coordinated, patient-centered care to all Americans is one of the most complex challenges that the Congress will face. It is a challenge that has proven too challenging, too difficult, and too politically risky for past Congresses and Presidents.

In March 2008 the Medicare Board of Trustees released a warning that Medicare’s finances are unsustainable. The report stated “The longer action is delayed, the greater the required adjustments [will be], the larger the burden on future generations, and the more severe the detrimental economic impact on our nation.” And yet the only response Congress made to this warning was to consider eliminating the requirement that the Trustees warn Congress when the financial situation worsens.

In other words, instead of heeding the warning, the health care leaders in Congress wanted to eliminate and thus ignore the warning. Both demographic changes (the impending retirement of the baby boomers) and rising health care costs per beneficiary contribute significantly to future fiscal calamities. Ignoring these facts is irresponsible and will only make future efforts to improve our health care system more complicated.

The Kaiser Family Foundation’s Employer Health Benefits 2007 Annual Survey determined that between 1998 and 2007, U.S. health premiums rose 98 percent compared to wages which increased only 23 percent. The average family health insurance policy now costs more than the earnings of a full-time minimum-wage worker.

In anticipation of the challenge facing both the next President and Congress, ADA has developed its own set of tenets by which it will analyze and critique any health care reform package presented to Congress.

These tenets focus on preventive and interventional health promotion and care and the role of the Registered Dietitian in maintaining health and wellness; disease prevention; and chronic care management throughout the continuum of life – preconception to end of life care. They are summarized as follows with more detailed explanations on the pages referenced:
These tenets are:

1. **The health of all Americans should improve as a result of our health policy choices.** Sufficient resources must be made available to ensure optimal health.

2. **Access to quality health care is a right that must be extended to all Americans.**

3. **Nutrition services, from pre-conception through end of life, are an essential component of comprehensive health care.**

4. **Stable, sufficient and reliable funding is necessary for our health care system to provide everyone access to a core package of benefits.**

5. **Health care must be patient-centered.**

This report is purposely narrow in its focus inasmuch as it is limited to only those issues that most directly affect ADA’s professional membership. ADA has not tried to address all the issues involved in health care reform. Issues such as pre-existing conditions, or interstate purchasing of health care policies, to name just two, are important issues for Congress to address, but are not issues in which registered dietitians have particular knowledge to guide the debate.

In his book *Saving Lives & Saving Money* Newt Gingrich argues that we need to transform not reform health care. He argues

> Reforming is a process of trying to make the current pattern work. Transforming is developing a new and very different pattern. Making a better horse and buggy was reforming. Inventing the internal combustion engine for cars, trucks, and airplanes was transforming.

The five tenets addressed in this report are intended to be transforming and not reforming.

Based on the five aforementioned tenets, the Health Care Reform Task Group recommends that the following policy positions be adopted by ADA as essential to any national health care reform package:

1. **The primary focus of any health care initiatives must be to improve the health status of Americans.** The vital and unique role that nutrition plays in improving and maintaining an individual’s health as well as the health of all Americans should be explicit in US health policy.

2. **Every American has a fundamental right to the best quality of health care available.** This right includes access to:

   - Healthy food, and
   - Qualified health professionals, including Registered Dietitians

3. **Nutrition services are critical to comprehensive health care delivery systems.** Health maintenance, wellness, disease prevention and early detection, delay in disease progression, and intervention in chronic care management are necessary components of a comprehensive health policy.

4. **The nation has to address the increased costs of health care and act now to:**

   - Expand coverage of nutrition services to a broader range of services where MNT will improve health outcomes.
   - Improve the coordination of health care and disease management. Include nutrition care provided by Registered Dietitians in team based programs and cover preventive and interventional nutrition services by individual RD providers.
• Improve and expand health information technologies and fully integrate nutrition status data into both medical records and personal health record systems. Health information technologies should be geared toward improving health and health care quality, reducing unnecessary expenses and inefficiencies in the delivery of care.
• Support a viable economic infrastructure that patients can count on through sound, sustainable funding.
• Fair market value is the appropriate standard for nutrition services reimbursement.

5. Nutrition education, nutrition assessment, nutrition counseling and nutrition interventions are examples of the unique knowledge, training and skills RDs possess and will prove to provide unmatched value to the patient.
Former Speaker of the House of Representatives Newt Gingrich has said he named his book about health care reform “Saving Lives & Saving Money” and not “Saving Money & Saving Lives” because you always want to save lives first. Perhaps that is the best way to sum up what ought to be the number one priority in reforming health care—improving the health status of Americans.

The first goal of health care reform must be to improve health status through healthy behaviors, health promotion, and public health.

Unfortunately, health care reform debates often start and stop with discussions about how to reduce costs. Saving lives and saving money are not mutually exclusive. Reforms can do both. However, to the degree that there is tension between the two, saving lives must prevail with the understanding that hospice and palliative care are needed parts of a patient centered system to provide dying patients with alternatives to disease-oriented treatments. Health care dollars should not be spent to prolong life for mere sake of prolonging life by use of extraordinary medical interventions. A balance must exist between saving money by not providing extraordinary and often painfully futile life prolonging measures and greater access to and understanding of palliative care.

We know that life expectancy is higher than ever before and has been increasing steadily for decades. We also know that improved sanitation and diagnostic measures which resulted in lower rates of infectious diseases are a major cause for this increased life expectancy. Unfortunately, the dramatically increasing incidences of preventable chronic diseases threaten this trend.

Chronic diseases such as diabetes, heart disease and cancer are now among the top causes of death in the U.S. Since these chronic diseases are largely preventable, any effort to reform health care must include measures to address how best to improve upon the preventive measures already in place.

That nutrition must be included when designing comprehensive health care that includes preventive services cannot be overstated. The World Health Organization sees nutrition as the foundation of health. This fact is well known and convincing: poor nutrition equals poor health and greater disease and the converse is just as true optimal nutrition equals good health and less disease. The importance of this statement must be the number one factor considered by Congress in debating health care.

The World Health Organization has identified the top 5 causes of death as chronic diseases—all of which are preventable, or at least delay-able:

- Heart Disease
- Cancer
- Stroke
- Chronic respiratory disease
- Diabetes

According to a Milken Institute report, preventable chronic disease in the U.S. in 2003 cost $1.3 trillion. Numerous studies have shown that nutrition oriented behavioral interventions and other lifestyle changes can reduce the incidence and severity of diabetes and heart diseases. Yet, many health
insurance programs, including Medicare and Medicaid do not cover preventive nutrition counseling or guidance for exercise.

When patients are provided counseling on nutrition, the information must be presented in an actionable format that they can understand and use to improve health outcomes. In other words, they must be able to understand and use the health and nutrition information presented to benefit from the counseling. Health literacy is the ability to read, understand, and act on health information. The Medical Library Association defines health information literacy as:

...is the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to specific situation; and analyze, understand, and use the information to make good health decisions.

Poor health literacy is a widespread problem that affects people of all social classes and from all ethnic groups. According to the Institute of Medicine, functional health literacy is worst among the elderly and low-income populations, impacting more than 66 percent of U.S. adults aged 60 and over and approximately 45 percent of all adults who live in poverty. Thus, the populations most in need of health care are least able to read and understand information needed to function as a patient.

A comprehensive health care policy must address intervention at all stages of life, including staying healthy, getting better, managing illness, and coping with end of life issues. ADA is a partner in a coalition called “Partnership to Fight Chronic Disease”. That coalition’s policy statements clearly identify some of the issues to be incorporated in a comprehensive reform package, including:

- Advance sustainable "Next Generation" chronic disease prevention, early intervention, and management models throughout the health care system and public health infrastructure
- Promote healthy lifestyles and disease prevention and management in every community
- Encourage and reward continuous advances in clinical practice and research that improve the quality of care for those with prevalent and costly chronic diseases
- Accelerate improvements in quality and availability of health information technology throughout the health care system
- Reduce health disparities by focusing on barriers to good health

If these goals are to be reached, initiatives outside the traditional health care delivery system must be incorporated into a comprehensive approach. This approach must include public health initiatives directed at the social norms and standards that directly impact the overall health of a community. The focus of these public health initiatives should be on prevention through the promotion of healthy behaviors.

There are lots of measures of the health status of a population. Avoidable deaths are certainly one. The United States places last among 19 countries in deaths that could have been prevented by access to timely and effective healthcare. According to the study done by Ellen Nolte and Martin McKee of the London School of Hygiene and Tropical Medicine, if the rate of preventable deaths in the U.S. improved to the average of the top three countries -- France, Japan and Australia -- 101,000 fewer U.S. residents would die annually. The reasons for this poor performance are due to two major factors - a large percentage of people who are uninsured, and a lack of preventive services even for those who are insured.

Proper nutrition is essential to good health. We cannot improve the health status of Americans without improving their nutritional status. Obesity, not hunger, is the number one cause of malnutrition in the US and rates of obesity have reached near epidemic levels. Someone who is 40% overweight is twice as likely to die prematurely as is an average-weight person. According to the Center for Disease
Control, in 2000, the most common actual causes of death in the United States were tobacco (435,000), poor diet and physical inactivity (400,000).

A sufficient, safe and varied food supply not only helps to prevent malnutrition but also reduces the risk of chronic disease.

Obesity increases the risk of many diseases and health conditions. These include—

- Coronary heart disease
- Type 2 diabetes
- Cancers (endometrial, breast, and colon)
- Hypertension (high blood pressure)
- Dyslipidemia (for example, high total cholesterol or high levels of triglycerides)
- Stroke
- Liver and Gallbladder disease
- Sleep apnea and respiratory problems
- Osteoarthritis (a degeneration of cartilage and its underlying bone within a joint)
- Gynecological problems (abnormal menses, infertility)

If health reform is going to be successful in improving the health status of Americans, then great attention must be given to improve the nutritional status of Americans and reducing the rates of obesity.

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Therefore it is recommended that ADA adopt the following:

_The primary focus of any health care initiatives must be to improve the health status of Americans. The vital and unique role that nutrition plays in improving and maintaining an individual's health as well as the health of all Americans should be explicit in US health policy._
The most famous phrase in American culture is “Life, liberty, and the pursuit of happiness”. As articulated in United States Declaration of Independence, it is the embodiment of the ideals on which our government was formed. These three concepts are listed among the “inalienable rights” of man; inalienable meaning a right that cannot be taken away. Access to comprehensive health care is an essential element to both life and the pursuit of happiness. The right to life and the pursuit of happiness are predicated on having meaningful access to comprehensive health care. Health is the first of all liberties.

In 2003, the ADA Board of Directors adopted a position paper that stated in part:

*It is the position of the American Dietetic Association that all children and adolescents, regardless of age; gender; socioeconomic status; racial, ethnic, or linguistic diversity; or health status should have access to food and nutrition programs that ensure the availability of a safe and adequate food supply that promotes optimal physical, cognitive, and social growth and development. Appropriate food and nutrition programs include food assistance and meal programs, nutrition education initiatives, nutrition screening and assessment followed by appropriate nutrition intervention, and anticipatory guidance to promote optimal nutrition status…Food and nutrition programs serve as a means to prevent or reduce hunger and food insecurity, but also as a vehicle for nutrition education and promotion of physical activity designed to prevent or reduce overweight and prevent chronic disease. It is the role of the registered dietitian to support adequate and sustained funding for food and nutrition programs, universal health care reimbursement for nutrition services, and the use of research and surveillance programs to evaluate and improve these programs.*

Access to adequate health care is no less important than access to food. The two are fundamental to life itself and are so intertwined that one without the other is insufficient. As included in the UN’s Declaration of Human Rights, people also have a right to the access to food. That right to access to food might be viewed as outside the arena of reforming health care, but it is essential to maintaining health. Ensuring that all Americans also have access to a healthy diet must be included in a comprehensive health care policy.

Although not sanctioned as part of any national health care policy or program, the U.S. has had for a number of years a de facto policy of universal health care coverage. Any individual in need of health care can go to an emergency room and receive care. However, this type of universal coverage is highly inefficient and extremely expensive. Furthermore, it fails to provide a standardized level of
health care. Our current guideline for allowing people without health insurance access to emergency room care is not a policy at all, but a lack of policy of how to address the problem of the uninsured.

Providing universal health insurance is not a luxury, it is a necessity. Opponents of universal coverage argue that the U.S. cannot afford universal coverage. The truth of matter is that we cannot afford to continue paying for the uninsured. The Institute of Medicine estimates that the uninsured cost $130 billion annually in medical bills and lost wages. Uninsured workers tend to lose work more often than the insured.

The health insurance industry has proposed guaranteeing coverage for every American, regardless of medical condition, in return for an enforceable requirement that everyone have a policy. The issue of pre-existing conditions which has been a barrier to changing jobs and thus health insurance coverage for millions of Americans can and should be eliminated with universal coverage. No one should be denied health insurance solely on the basis of pre-existing conditions. However, for that to work, there must be a enforceable prerequisite that everyone have coverage to prevent people from trying to “game” the system by avoiding paying for insurance until it is needed.

There are numerous options available to Congress in addressing the issue of providing health care to the uninsured. Health care coverage will inevitably involve tax policies and insurance reform, issues beyond the scope of this discussion.

ADA however does advocate for reforms that reflect societal and individual values that endorse access to comprehensive health care as a right that must be available to all Americans. One such social value is the elimination of health disparities. Currently in the US, racial and ethnic minorities and economically disadvantaged individual are disproportionately unable to obtain high-quality medical care. As a result, there are measurable differences in both health status and health care among demographics.

Consistent with extensive research and findings in previous NHDRs, the 2006 report finds that disparities related to race, ethnicity, and socioeconomic status still pervade the American health care system. Although varying in magnitude by condition and population, disparities are observed in almost all aspects of health care, including:

- Across all dimensions of quality of health care including: effectiveness, patient safety, timeliness, and patient centeredness.
- Across all dimensions of access to care including: facilitators and barriers to care and health care utilization.
- Across many levels and types of care including: preventive care, treatment of acute conditions, and management of chronic disease.
- Across many clinical conditions including: cancer, diabetes, end stage renal disease (ESRD), heart disease, HIV disease, mental health and substance abuse, and respiratory diseases.
- Across many care settings including: primary care, home health care, hospice care, emergency departments, hospitals, and nursing homes.
- Within many subpopulations including: women, children, elderly, residents of rural areas, and individuals with disabilities and other special health care needs.

It should be the goal of any universal coverage plan to not only ensures everyone has access to care, but that the care which is offered addresses the issue of disparities. Congress must design a system that provides equal access to health coverage and health care.

ADA also notes the difference between coverage and access. Many uninsured are covered by their state’s Medicaid program. However, since provider participation is so low, (due largely to low reimbursement rates), access is limited. All individuals deserve both coverage and access to quality health care and that access and coverage should be equitable, regardless of an individual's
demographic characteristics, race or geographic location. The issue of adequate compensation for physician and non-physician care must be addressed. If providers will not accept patients because the reimbursement rate is too low or the bureaucratic/administrative burdens of the program are too great, then we will still have a system that does not address the health care needs of our population.

Therefore it is recommended that ADA adopt the following:

*Every American has a fundamental right to the best quality of health care available. This right includes access to:*

- Healthy food, and
- Qualified health professionals, including Registered Dietitians
Currently the U.S. has a highly specialized, surgical/diagnostic procedures care based system that is designed to address treatment of episodic and chronic conditions. The adage that the U.S. has a sick care system, not a health care system, correctly reflects this fact. In November 2006, ADA released a position paper that stated primary prevention is the most effective, affordable course of action for preventing and reducing risk for chronic disease.

As noted earlier, chronic diseases, many which are preventable are the leading causes of death and disability in the United States. Combined, these diseases account for the vast majority of health care spending. More importantly, according to the Centers for Disease Control and Prevention, they negatively affect the quality of life for 133 million Americans and are responsible for seven out of every ten deaths in the U.S. – killing more than 1.7 million Americans every year.

Many incidences of chronic illness, most notably heart disease, stroke, diabetes, and some forms of cancer, can be avoided or delayed through physical activity, proper nutrition, avoiding tobacco use and excessive alcohol consumption, and through early detection of cancer and other diseases.

Despite these well known and well understood problems, the issue of preventing chronic disease has not been high on the agenda of most policymakers as an issue of primary concern. As the Milken Institute report on an Unhealthy America stated:

*This failure to contain the containable is undermining prospects for extending health insurance coverage and for coping with the medical costs of an aging population. The rising rate of chronic disease is a crucial but frequently ignored contributor to growth in medical expenditures.*

It is estimated that 83 percent of Medicare beneficiaries have at least one chronic medical condition. Among the general population that number is about 45 percent. Consequently, any effort to reduce health expenditures must address how to prevent and manage chronic disease. Meaningful reform must result in a health care system that uses evidence-based guidelines for preventing chronic diseases from developing and/or progressing.

Testing, diagnosing, relieving symptoms, and managing a chronic condition are hallmarks of contemporary health care. While these functions are appropriate for acute and episodic health problems, a notable disparity occurs when applying this model of care to the prevention and management of chronic conditions. Preventive health care is inherently different from health care for acute problems, and in this regard, the current U.S. health care system is woefully inadequate.

Any meaningful health care reform must include a paradigm shift emphasizing both prevention and management of chronic diseases. This should involve both the family physician and the medical specialties with coordinated services provided by both physician and non-physician practitioners. Comprehensive preventive services should be provided along the spectrum of care for all ages. These
services must include early and continuing nutritional counseling and intervention related to preventing, treating or delaying the progression of chronic diseases.

A comprehensive prevention oriented health care policy recognizes the various stages of preventive care, including—but not limited to—staying healthy, recovering from a disease or condition, and in some cases chronically managing an illness. Nutrition counseling and education (using evidenced based practices and protocols) for each of these stages must be a part of any comprehensive preventive policy.

Prevention is only one of the keys to resolving the health care financial crisis facing America. Nutrition services also include delaying the progression of diseases as well as intervention in chronic disease management. Nutrition services further provide assistance in health maintenance.

Another issue is the cost of care at the end of life. A significant percentage of health care dollars is spent on patients in the last few weeks or months of their lives.

Comprehensive health care does not mean heroic measures to prolong a terminally ill person’s life. A compassionate health care policy must help patients, families and doctors to recognize when it is time to move away from death-prolonging treatments that offer little to no benefit. Furthermore, Congress needs to address the issue of tort reform to insulate doctors and other health care providers from unreasonable lawsuits as a result of end of life decisions.

In addressing this problem, Congress must recognize the fact that further medical intervention for terminally ill patients does not mean a reduction in care or in providing suboptimal care. Instead it provides for a great balance the real needs of the patient and the types of medical procedures prescribed. Our health care system need to develop advance directives that promote autonomy and patient-centered are through respect for decision-making preferences and the right to refuse life prolonging treatments. In August 2005, ADA adopted a position that stated:

*It is the position of the American Dietetic Association that older Americans receive appropriate care; have broadened access to coordinated, comprehensive food and nutrition services; and receive the benefits of ongoing research to identify the most effective food and nutrition programs, interventions, and therapies across the spectrum of aging. Food and water and nutritional well-being are essential to the health, self-sufficiency, and quality of life for the fast growing, heterogeneous, multiracial, and ethnic populations of older adults. Many people, as they age, remain fully independent and actively engaged in their communities; however, others fare less well and need more support. A broad array of appropriate, culturally sensitive food and nutrition services, physical activities, and health and supportive care customized to the population of older adults are necessary.*

*National, state, and local policies that promote coordination and integration of food and nutrition services into health and supportive systems are needed to maintain independence, functional ability, chronic disease management, and quality of life. Dietetics professionals can take the lead by researching and developing national, state, and local collaborative networks to incorporate effectively the food and nutrition services across the spectrum of aging.*

This continues to be the position of ADA regarding care for patients nearly the end of life.

It is recommended that the ADA Board of Directors adopt the following position:

*Nutrition services are critical to comprehensive health care delivery systems. Health maintenance, wellness, disease prevention and early detection, delay in disease progression, and intervention in chronic care management are necessary components of a comprehensive health policy.*
The U.S. spends more on health care per person than any other nation in the world. There are many causes for the continued increase in health care costs. Three of the more significant factors contributing to increase health care costs are the aging population, Americans’ preference for new technologies, and the dramatically increasing prevalence of preventable chronic diseases.

In 2006, the Medical Payment Advisory Committee (MedPAC) sent a report to Congress that stated:

*Health care spending has been rising more rapidly than growth in national income for many decades, and all indications suggest that it will continue to do so into the future. The continuation of this trend, combined with the retirement of the baby boomers and Medicare’s new prescription drug benefit, will lead the Medicare program to require unprecedented shares of federal spending.*

While the U.S. leads the world in spending on health care, it is the only wealthy, industrialized nation that does not ensure that all citizens have coverage. Health care costs have been rising for several years. Expenditures in the United States on health care surpassed $2 trillion in 2006, almost three times the $714 billion spent in 1990, and over eight times the $253 billion spent in 1980. And yet, despite this investment, over 40 million Americans are without health insurance, and that number continues to increase by about 3 million every year.

Most people in the U.S. receive their health care benefits from their employer, or from a federal or state health insurance program. Employer-funded coverage is the structural mainstay of the U.S. health insurance system. According to 2005 data from the U.S. Census Bureau, the most recent official data available, employer-provided health benefits cover 175 million Americans, or about 60 percent of the population. For workers earning $20,000 per year — roughly $10 per hour — the employee’s share for family coverage is more than 16 percent of their pre-tax income. The affordability of health care is a major issue that must be addressed within the context of universal health care.

One factor that can have a significant impact on holding costs to a minimum is better coordination of care. In her book *One Nation Uninsured: Why the U.S. Has No National Health Insurance*, Jill Quadagno states about one-third of adults in the U.S. have problems with coordination of care, meaning test results and medical records were not available when needed; patients received duplicate and therefore unnecessary tests and procedures; among other problems. Both practitioners and policymakers, over the last several years, have tried to find new and better methods of disease management. A concept called “the medical home” is one model demonstrating methods to coordinate care.
According to a joint statement by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association, in February 2007, the Patient-Centered Medical Home (PC-MH) is an approach to providing comprehensive primary care for children, youth, and adults. The PC-MH is a health care setting that facilitates partnerships between individual patients and physicians. As noted by the American Academy of Pediatrics:

A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

The medical home concept can accommodate a variety of practice settings and styles. Medical homes can be community health centers. These centers need to be fully funded inasmuch as they may be the only provider of health care in many rural areas. Even if Congress passes a “universal” coverage bill, there will always be some who fail to find access to a provider. Community health centers have proven to be an excellent source of health care for those who do not have a primary care provider or access to other health care providers.

In most instances a medical home provides for each patient to choose his or her own personal physician that coordinates a team of other health care providers. This concept can include medical care at all stages of life including preventive services, acute care, chronic disease management, and end of life care. Costs savings are realized as all aspects of care are coordinated.

Beyond reforming the delivery and organization of health care, true reform also addresses the type of care that is provided. Investing in preventive services as mentioned above is an initial and necessary step. For example, diabetes costs our health care system $116 billion a year and there are 57 million Americans who are prediabetic and not receiving proper treatment or counseling to prevent their condition from progressing to type 2 diabetes. Preventing the progression of prediabetes to type 2 diabetes can save billions of dollars every year. The same can be said for the treatment and prevention of many other chronic conditions, such as obesity and heart disease. But prevention alone cannot ensure financial stability. Prevention, while cost effective, is not “free”.

Determining appropriate coverage consider evidence-based reviews when appropriate and when sufficient evidence is available upon which a decision can be based. The use of evidence-based guidelines (when available) may improve the quality of the health care and help control inflationary pressures. Utilization of evidence-based guidelines and procedures should be encouraged as a core competency for all health care providers.

The U.S. lacks a standardized level of care, meaning that each doctor can determine to a large degree how to care for different prognoses. This in turn has lead to differing levels of care from one region of the country to another and from one medical group to another. The Congressional Budget Office has conducted studies that determined “per capita health care spending varies widely across the United States and yet the very substantial variation in cost per beneficiary is not correlated with health outcomes overall”.

This being the case, it illustrates a significant opportunity to reduce cost nationally while not adversely affecting health outcomes. Geographically dissimilar professional norms largely dictate different levels of medical care and likely account for the variance in cost per beneficiary. Evidence-based standards of best practices can reduce unnecessary medical procedures and expenditures without lowering the quality of care. Health care reform must include a systemic implementation of national, evidence-based medical practice standards (when available and appropriate) to improve quality, control costs, and reduce litigation risks.

Implementation of national standards underlines the need to ensure that all providers are the best trained in their field. Credentialing is an essential component in determining whether or not an individual has met the minimum competency standards to practice a profession. Many states have either licensing, credentialing or scope of practice laws in place as a qualifying measure for being a
medical provider. A number of professional associations have a national certification process that documents entry-level competency. Credentialing is an important component of a health care system that not only protects the interest of the insurer, but those of patients as well. Where credentials are available, they should be used as a gatekeeper to provider status.

Another ingredient to controlling health care costs is greater reliance on health information technology. An Institute of Medicine study estimated that 98,000 Americans die annually from medical errors, caused by bad provider handwriting, incomplete charting, or other IT resolvable issues. Improvements in and expansion of health information technology are essential elements for any overall solution in controlling health care costs and improving the quality of care.

According to the U.S. Department of Health and Human Services:

Health information technology (Health IT) allows comprehensive management of medical information and its secure exchange between health care consumers and providers. Broad use of health IT will:

- Improve health care quality
- Prevent medical errors
- Reduce health care costs
- Increase administrative efficiencies
- Decrease paperwork
- Expand access to affordable care.

Interoperable health IT will improve individual patient care, but it will also bring many public health benefits including:

- Early detection of infectious disease outbreaks around the country;
- Improved tracking of chronic disease management; and
- Evaluation of health care based on value enabled by the collection of de-identified price and quality information that can be compared
- Involvement of the patient in his own health care with interactive IT systems

Health IT is no panacea for controlling cost, but many cost containing proposals and recommendations, such as medical homes, are predicated on a more ubiquitous health IT system and utilization. Health IT has the potential to save millions of dollars. HHS estimates that widespread use of electronic health records would save about 100,000 lives annually through a decrease in medical errors and reduce health care spending by as much as 30%. Others have estimated that widespread adoption of health care IT would reduce spending by $81 billion annually over the next 15 years.

As Health IT matures, more attention must be paid to “nutrition informatics”. As explained by ADA’s President Martin Yadrick in a December 2008 JADA article, nutrition informatics is

*the effective retrieval, organization, storage, and optimum use of information, data, and knowledge for food and nutrition-related problem solving and decision making. Informatics is supported by the use of information standards, information processes, and information technology.*

Congress needs to provide additional resources to the Department of Health and Human Services National Coordinator for Health Technology. This office is responsible for building an interoperable health IT system to improve individual patient care, and bring many public health benefits including:

- Early detection of infectious disease outbreaks around the country;
- Improved tracking of chronic disease management; and
- Evaluation of health care based on value enabled by the collection of de-identified price and quality information that can be compared.
For this system to be effective, national technology standards and definitions of medical and nutritional terms must be established and individual providers trained on how to become proficient at using the new technology.

Another critical factor that must be addressed in health care reform is how to determine a fair reimbursement rate for physician and non-physician health care providers. Today, Medicare uses a highly complex and largely incomprehensible methodology to determine reimbursement rates and in adjustments to those rates. Reimbursement rates must provide for a balance between those who have to pay the reimbursement and those who receive the payments. Adjustments to those payments need to reflect fair market value. The current Sustainable Growth Rate formula used by Medicare has to be replaced with a methodology that is more comprehensible and accurate.

Low reimbursement rates are one of the leading causes for a shortage of physician and non-physician specialist in some areas, mainly rural, in the US. This issue must be addressed when designing a universal health care system. If people are to have access to health care, then health care providers have to be available.

There is no one solution to controlling health care cost, using evidence-based practices to establish national standards of care, implementation of concepts such as medical homes, controlling preventable chronic disease, and implementation of health information technology will help constrain increases in health care costs.

It is recommended that the ADA Board of Directors adopt the following:

*The nation has to address the increased costs of health care and act now to:

1. Expand coverage of nutrition services to a broader range of services where MNT will improve health outcomes.
2. Improve the coordination of health care and disease management. Include nutrition care provided by Registered Dietitians in team based programs and cover preventive and interventional nutrition services by individual RD providers.
3. Improve and expand health information technologies and fully integrate nutrition status data into both medical records and personal health record systems. Health information technologies should be geared toward improving health and health care quality; reducing unnecessary expenses and inefficiencies in the delivery of care.
4. Support a viable economic infrastructure that patients can count on through sound, sustainable funding.
5. Fair market value is the appropriate standard for nutrition services reimbursement.*
Patient-centered health care has a nice ring to it, but it can often mean different things to different people. In today’s environment, it is increasingly popular to argue that patients should have more control over their health care. Key element of health reform is changing the delivery system to provide a stronger and more reliable information infrastructure as well as reforming the delivery of care through better coordination and integration.

Patient-centered medical homes promise to change the status quo by enabling physicians to provide comprehensive primary care through stronger partnerships with their patients. The underlying rationale of a patient-centered health care system is to help beneficiaries receive better targeted benefits and improved health outcomes for their dollars. The principles involved in patient centered care are:

- each patient receives care from a personal physician;
- the personal physician leads a team of providers who are responsible for a patient's ongoing care;
- the personal physician is responsible for the "whole person";
- a patient's care is coordinated across the health system and community;
- quality and safety are hallmarks of the practice;
- enhanced access to care is offered through open scheduling, expanded hours, and new care options such as group visits; and
- the payment structure recognizes the enhanced value provided to patients.

According to the American College of Physicians, there is a difference between a medical home and a typical disease management programs.

Typical disease management programs utilize “case managers” provided by the patient’s health plan or a contracted disease management company. The best programs attempt to include the treating physician and his or her team, but the emphasis is usually on the relationship between the patient and the case manager, with periodic input requested from the patient’s physician. In the advanced medical home model, the care and coordination of that care continually resides with the patient's personal physician and his or her health care team. The patient and physician decide on specific health care objectives and then choose the best way to achieve these objectives. Advanced medical home practices will provide a range of options for their patients to support their personal health goals (e.g., health education, nutrition services, and disease management) either directly or through established relationships with external providers of these services, such as disease management companies. The patient, with support from the physician and other members of the health care team that may include nurses, social workers, care managers, dietitians, pharmacists, physical and occupational therapists, and other allied
health care professionals, then becomes engaged in his or her health care, and the health care system better serves the needs of each individual patient.

What distinguishes a medical home from a conventional practice is the more comprehensive approach to care from prevention through disease management, to health maintenance. The medical home concept is being tested nationally, including in the Medicare program, which is launching demonstration projects.

The Institute of Medicine considers patient centeredness as an essential component of quality care. It lists patient centered care among the six dimensions of quality. According to the IOM:

In contrast to care that is clinician centered or disease-focused, patient-centered care customizes treatment recommendations and decision making in response to patients’ preferences and beliefs. In such a partnership, clinicians’ decisions are informed by an understanding of patients’ needs and understanding of their environment, which includes home life, job, family relationships, cultural background, and other factors. This partnership also is characterized by informed, shared decision making, development of patient knowledge, skills needed for self-management of illness, and preventive behaviors.

It is recommended that the ADA Board of Directors adopt the following:

_**Nutrition education, nutrition assessment, nutrition counseling and nutrition interventions are examples of the unique knowledge, training and skills RDs possess and will prove to provide unmatched value to the patient.**_
True health care reform is ambitious. However, inaction and incrementalism which have characterized U.S. health policy in the past have resulted in the predictable result of both health care spending and the number of uninsured Americans reaching record levels. A reform proposal that attempts simultaneously to secure universal coverage, shift to a prevention oriented system, provide for sound financial footing and is patient-centered would attract significant opposition from numerous interest groups. Any comprehensive plan would as well.

However, unless Congress and the President are able to overcome these obstacles, health care will continue to cost more and provide less coverage. At some point in the near future, the shortcomings of the current system will align to mandate action at a much greater cost than if reforms come sooner.

The U.S. health care system is in a crisis that will only get worse if Congress fails to act. At stake is the quality of life for millions of Americans, the financial security of families and individuals currently without health care, the ability of both Federal and state governments to provide health care to those in need, and the competitiveness of American businesses.

For ADA members the stakes could not be higher. Dietitians are an essential provider of preventive and chronic disease management services. Any effort to reform health care must recognize the unique role that dietitians play.

If ADA is to participate in the Congressional debate over health care, however, its position must address more than the unique role of the dietitian. It is therefore recommended that the ADA Board of Directors adopt the following:

1. The primary focus of any health care initiatives must be to improve the health status of Americans. The vital and unique role that nutrition plays in improving and maintaining an individual’s health as well as the health of all Americans should be explicit in US health policy.

2. Every American has a fundamental right to the best quality of health care available. This right includes access to:
   - Healthy food, and
   - Qualified health professionals, including Registered Dietitians

3. Nutrition services are critical to comprehensive health care delivery systems. Health maintenance, wellness, disease prevention and early detection, delay in disease progression, and intervention in chronic care management are necessary components of a comprehensive health policy.

4. The nation has to address the increased costs of health care and act now to:
   - Expand coverage of nutrition services to a broader range of services where MNT will improve health outcomes.
• Improve the coordination of health care and disease management. Include nutrition care provided by Registered Dietitians in team based programs and cover preventive and interventional nutrition services by individual RD providers.

• Improve and expand health information technologies and fully integrate nutrition status data into both medical records and personal health record systems. Health information technologies should be geared toward improving health and health care quality; reducing unnecessary expenses and inefficiencies in the delivery of care.

• Support a viable economic infrastructure that patients can count on through sound, sustainable funding.

• Fair market value is the appropriate standard for nutrition services reimbursement.

5. Nutrition education, nutrition assessment, nutrition counseling and nutrition interventions are examples of the unique knowledge, training and skills RDs possess and will prove to provide unmatched value to the patient.
Patient-Centered Medical Home Strategic Plan

ADA Medical Home Workgroup
May 2009
Prepared by Medical Home Workgroup

Jeanine Ricketts Byrne, MA, RD, LD
Deborah Cummins, PhD
Mary H. Hager, PhD, RD, FADA
Harold Holler, RD, LDN
Diane Juskelis, MS, RD, CSP, LDN
Pamela Michael, MBA, RD
Sharon McCauley, MS, MBA, RD, LDN, FADA
Katie Paffhouse
Christine Reidy, RD, Chair
Patient-Centered Medical Home Strategic Plan

Introduction

In March 2009, the CEO appointed a staff Medical Home Workgroup charged to gather and assess information related to RDs current involvement in this model of care and to develop for the House of Delegates Leadership Team and the ADA Board of Directors a strategic plan for engaging members in this model. The workgroup’s research, findings and recommendations follow.

Background

The term medical home was first coined by the American Academy of Pediatrics (AAP) in 1967 and initially meant a central place for archiving a child’s medical record. Gradually the term broadened to include a partnership approach with families to provide primary health care that is accessible, family-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective. In its 2002 policy statement, the AAP expanded the medical home concept to include these operational characteristics: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. (1)

In 1978 the World Health Organization (WHO) underscored the basic tenants of the medical home and emphasized the important role of primary care in its provision. The WHO declaration affirmed primary care as the key to attaining adequate health and well-being a fundamental human right. The WHO identified primary care at the center of the health system and close to home. These precepts about primary care were embraced in the 1990’s by the Institute of Medicine (IOM) which specifically mentioned medical home. (2)

The IOM reports influenced the specialty of Family Medicine, and the term ‘Medical Home’ began to appear in the family medicine literature. The IOM described medical homes in the context of “continuous healing relationships” in which the patient’s needs and values are central.(3) The value of continuous healing relationships between patients and physicians is not only related to patient’s perceptions but to the quality of care they receive as well.(4) The ability of primary care to create sustained clinician-patient partnerships and provide whole-person oriented care is already eroding according to Medicare beneficiaries.(5) Without financing for electronic medical records that specifically supports the integration care for people with chronic diseases into primary care, and that support sustained integrative relationships, patients’ experiences in the fragmented healthcare system are likely to grow worse, particularly for people with multiple conditions. (6)

In 2002, family medicine undertook a study to develop a strategy to transform and renew the discipline of family medicine to meet the needs of patients in a changing health care environment. The result was “The Future of Family Medicine: A Collaborative Project of the Family Medicine Community”. The Future of Family Medicine Project states that every American should have a Personal Medical Home that serves as the focal point through which all individuals—regardless of age, sex, race, or socioeconomic status receive acute, chronic, and preventive medical care services as needed.(7)
The Chronic Care Model was another important contributor to the patient-centered Medical Home (PCMH). The elements of this model have been shown to improve the quality and cost-effectiveness of care for patients with chronic diseases. In 2004, the American Academy of Family Physicians (AAFP) used the elements of the model to describe how it might apply more broadly to models of primary care, and needed changes in how care is paid for to sustain it. This model also contributed to thinking about new models of care that can commit to becoming a PCMH, particularly those that will care for patients with complex and chronic conditions. These important efforts and studies have identified the core features that need to be present in a Patient Centered PCMH. The American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) have since developed their own models for improving patient care called the “Medical Home” (AAFP, 2004) or “advanced PCMH” (ACP, 2006). In March 2007, four organizations, the American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP) and American Osteopathic Association (AOA) developed joint principles to describe the characteristics of the patient centered PCMH. (Appendix A)

There are several definitions of the PCMH. The common themes are:

- The physician based practice focuses on the coordination of patient care according to the patient’s specific needs and medical priorities.
- The physician communicates directly with patients and their families and integrates care across settings and practitioners.

The PCMH Workgroup relied on the following definition from the National Committee for Quality Assurance (NCQA) (Appendix B):

**PCMH Model for Care**

A PCMH is not a house, hospital or other building and should not be confused with home-health or home-care. The PCMH is a model for care provided by physician practices that seeks to strengthen the physician-patient relationship by replacing episodic care based on illnesses and patient complaints with coordinated care and a long-term healing relationship. Each patient has an ongoing relationship with a personal physician who leads a team that takes collective responsibility for patient care. The physician-led care team is responsible for providing all the patient’s health care needs and, when needed, arranges for appropriate care with other qualified physicians.

A PCMH also emphasizes enhanced care through open scheduling, expanded hours and communication between patients, physicians and staff. The components of the PCMH are illustrated in the transforMED diagram (Appendix C).

The PCMH model for health care delivery is designed to improve the quality of the U.S. health care system and reduce health care delivery cost. This model departs from the current fee for service system which bases physician payment on the number of patients they see and the individual services or resources they use. The PCMH model adds a care coordination payment to the physicians. This provides an incentive for physicians to maximize quality care, reduce costs for repetitive services, and decrease hospital admissions and emergency room visits.
Case for Change to the PCMH Model

Health outcomes in the U.S. continue to fall behind those of other developed—and some less developed—countries, despite unrivaled spending. (11) Our slippage in general health and longevity relates largely to the fact that we permit large sectors of our population to go without insurance and access to care. (12) Having a usual source of care, the most essential element of a PCMH, is extremely influential in the care people receive. In fact, having a usual source of care, independent of other factors such as health insurance, is associated with a greater likelihood that people receive care in nearly every setting. People who utilize care but do not have a usual source of care, experience real barriers to getting care when they need it. (13) This is true for children and adults. People who have a usual source of care are also more likely to receive preventive care services, independent of having insurance. (14) For many people, the usual source of care will be a personal physician, and having chosen one’s physician is the single predictor most strongly related to having high overall satisfaction. (15,16)

It is well established that having a regular source of care and continuous care with the same physician over time has been associated with better health outcomes and lower total costs. (17) There is also substantial evidence that increased use of primary care physicians resulted in reduced hospitalizations and reduced spending for other non–primary-care specialist services with improvements in morbidity and mortality rates. (18,19) Unfortunately, continuity has been found to be quite low, particularly for Medicare Beneficiaries many of whom have chronic health conditions that would benefit most from having a personal physician to coordinate their care.

One study of Medicare beneficiaries found that these patients saw a median of two primary care physicians and five specialists working in four different practices. A median of 35% of beneficiaries’ visits each year were with their assigned physicians; for 33% of beneficiaries, the assigned physician changed from one year to another. When the 2006 Commonwealth Fund Health Care Quality study team combined four characteristics of a PCMH in combination, only 27% of working age adults—an estimated 47 million people—had a PCMH. Another 54% of adults have a regular doctor or source of care, but they do not have the enhanced access to care provided by a PCMH. (20) The system will have to address the looming imbalance between the number of chronically ill elderly and available caregivers. If very sick elderly people cannot receive competent and caring day-to-day assistance, then other health care reforms are unlikely to have much impact. (21)

The Commonwealth Fund Study found that health care settings with features of a PCMH—those that offer patients a regular source of care, enhanced access to physicians, and timely, well-organized care—have the potential to eliminate disparities in terms of access to quality care among racial and ethnic minorities. This suggests that expanding access to PCMHs could improve quality and increase equity in the health care system. (22)

One of the most unfair ironies of a health care system that now spends $2 trillion per year—nearly $7000 per citizen on health care is the burden it places on patients to transfer information between their health care providers. The patient is the most vulnerable person in the equation and
the one least trained in the complex culture and language of medicine, yet he/she is expected to verbally relate their sequence of care. If they are lucky, it is on bits of paper or the electronic equivalent. It is no wonder that these hand-offs of care are often dangerous for patients. The standards for organizing patient information are still being developed in the U.S. while other developing countries already enjoy interoperable systems. The PCMH should ensure that the health care team pulls together to best serve patient needs in all arenas. In the PCMH, integration will have to be a system-property, with information systems, teams, and organizational linkages promoting integration.(23)

“Other nations ensure the accessibility of care through universal health insurance systems and through better ties between patients and the physician practices that serve as their long-term medical home. It is not surprising, therefore, that the U.S. substantially underperforms other countries on measures of access to care and equity in health care between populations with above-average and below-average incomes.”(24)

The rationale for the benefits for PCMH has been found in:

- Greater access to needed services
- Better quality of care
- A greater focus on prevention
- Early management of health problems
- The cumulative effect of the main primary care delivery characteristics
- The role of primary care in reducing unnecessary and potentially harmful specialist care.

Where the [primary care]-team functions as a “navigator” through secondary and tertiary care and other sectors, it can be a strategy for achieving cost-effectiveness. (25)

While most Americans utilize primary care doctors as their personal physicians, the hazards of doing so in the current healthcare environment are well documented. The Future of Family Medicine report concluded in 2004 that, “Unless there are changes in the broader health care system and within the specialty, the position of family medicine in the United States will be untenable in a 10- to 20-year time frame.”(26) Internal medicine has recently reached similar conclusions and is witnessing an unprecedented migration of their young trainees away from primary care.(27;28) The PCMH will have to be hospitable to this country’s next generation of physicians if it is to be realized for patients.(29)

With health care reform a necessary reality, consumers, payers, and physicians are looking for ways to improve care, improve value, and transform practice. PCMH has attracted support from all three major constituencies, and has inspired both Federal and State legislation. Under Section 204 of the Tax Relief and Health Care Act of 2006, Medicare was directed to support a PCMH Medicare Demonstration Project. This three year project involves care management reimbursement and incentive payments to physicians while evaluating the health and economic benefits of providing targeted, accessible, continuous, and coordinated, family-centered care to high need populations. (30)
Environmental Scan

Other Healthcare Professional Associations:

The ADA Medical Home Workgroup contacted several other health care associations to determine their level of involvement and position. The questions posed were:

1. Is your association supporting the PCMH? Why? Or Why not?
2. What actions have you taken to demonstrate support or lack of support?
3. Has your association undertaken a PCMH education initiative for members? If yes, please describe.
4. Does your association have a position paper?

The American Psychological Association (APA) works with a coalition named PARCA (Patient Access to Responsible Care) that represents non-physician practitioners. The coalition submitted letters to congress and the Obama administration supporting the inclusion of non-physician practitioners in the PCMH model, if the model is to be a part of health care reform. (Appendix D)

The American Chiropractic Association (ACA) is likely to support the Joint Principles of the PCMH Model, but the Association has concerns about limiting the types of providers that would be allowed to function in this capacity. The Association believes patients should have a right to choose their provider and are also concerned for the implications for under-served areas. For this reason, the ACA looked at the Iowa model of the PCMH which includes a variety of licensed practitioners (family care, general practitioner, internist, obstetrician, gynecologist, and advanced practice registered nurse, physician assistant and chiropractor).

The ACA summarizes their support for the Iowa model PCMHs in contrast to the version of PCMHs in the Center for Medicare & Medicaid Services (CMS) pilot for the following reasons:

- If certification is required for any provider, then all providers should be able to participate.
- The key principle behind the PCMH concept is patient-centered care. Patients should be able to select their provider.
- Access to a PCMH in a rural area is critical; for states like Iowa in particular it makes more sense for the federal government to follow the lead of the Iowa state government in terms of which providers can deliver care.

American Podiatric Medical Association (APMA)
The APMA had a document created by its consultants titled, “The Medical Home Concept: A Primer for APMA” (Appendix E) which outlines the characteristics and roles of PCMHs, states what supporters believe the model will accomplish, and shows the evidence to support the new model and the views of federal policy makers. The APMA has two concerns regarding the PCMH model:
1. Will policy makers’ interest in helping primary care lead them to (prematurely) mandate a nationwide PCMH program for Medicare—even before there are any results from the already mandated demonstration project?

2. Will PCMHs compromise Medicare beneficiary and other patient access to the services of doctors of podiatric medicine? The APMA remains optimistic that this issue will be addressed via a thorough, independent assessment of the Medicare PCMH demonstration project. The APMA believes the PCMH concept requires additional study to determine how to recognize and include all medical specialties, and that it is imperative that reportable quality measures be identified and approved.

American Academy of Physician Assistants (AAPA)
The AAPA policy statement regarding the PCMH states: "AAPA supports the PCMH concept as a means to improve the quality of patient care. A PCMH provides patient- and family-centered care that is culturally appropriate, is coordinated and integrated, is committed to quality and safety, has enhanced access to affordable health care services, and is team care led by a physician. AAPA believes these principles can apply to any setting where continuing, longitudinal primary or specialty care is provided."

While AAPA supports the concept of the PCMH model, they have concerns with principles promulgated by physicians. AAPA thinks that the principles are focused too much on payment and the physician role rather than on the patient and quality of care. AAPA strongly supports access and affordability of care and does not believe the concept should be limited to the primary care setting; all specialists (e.g. endocrinologists, cardiologists) should be included.

AAPA also joined the Patient-Centered Primary Care Collaborative (PCPCC) in 2008, and the Executive Director of the PCPCC will speak at the AAPA conference in San Diego in 2009.

National Association of Social Workers (NASW)
The NASW is aware of this model, and has chosen to stay on the sidelines pending health care reform action. Member education has not been initiated.

American Physical Therapy Association (APTA)
The APTA has concerns about the impact of PCMH on physical therapy related to whether physicians will refer to Physical Therapist (PT) or will attempt to provide treatment without a PT. The APTA is monitoring the situation; however, no specific strategy or action is planned.

American Nursing Association (ANA)
The ANA is working to position nursing within the PCMH (Appendices F, G).

Expert interviews
In order to better understand the environment, the ADA Medical Home Workgroup contacted the following external sources who have direct professional experience in the PCMH model:

- Michael Fleming, MD – Chief Medical Officer, Antidote Education Company, Shreveport, Louisiana
- Marsha Schofield, MS, RD, LD – Summit county Health District, Stow, Ohio
Registered Dietitians Survey

The ADA PCMH Workgroup sent a survey to a random sample of 7,800 registered dietitians (Appendix H).

- 1056 RDs (13.5%) responded to an online survey focused on the PCMH model for care
  - 805 RDs (77.3%) were unfamiliar with the PCMH concept
  - 236 RDs (16.5%) are familiar with the concept but do not work in a PCMH setting
  - 67 RDs (6.3%) participate in a PCMH model for care in 19 different states
    - Of the (67 RDs; 6.3%) respondents who work in a PCMH model for care
      - (36 RDs; 73.5%) work in direct patient care
      - (8 RDs; 16.3%) in program development and administration
      - (5 RDs; 10.2%) in a non-specified capacity
  - The PCMHs equally serve the geriatric, adult and pediatric populations. The following conditions are the most frequently treated:
    - Cardiovascular (22 RDs; 44.9%)
    - Diabetes (27 RDs; 55.1%)
    - Obesity (24 RDs; 49%)
  - RD involvement;
    - Employer was contacted to provide services (21 RDs; 56.8%)
    - Physician or other healthcare professional contacted them to include their services in the PCMH (12 RDs; 32.4%)
    - RD approached a physician to include their services in the PCMH (7 RDs; 18.9%)

The respondents identified resources they found valuable to their involvement:

- The Maternal and Child Health Bureau of Health Resources and Services Administration (HRSA) have many tools and resources pertaining to PCMH.
- Pediatric Nutrition Practice Group (PNPG DPG) Building Block for Life, Vol 30, No 1, 2007 PCMH: Focus on Nutrition Services in the Community (Appendix I)
- The Center for Children with Special Healthcare Needs Newsletter from the PCMH Project
- Tennessee provides forms for all assessment and reviews
- Diabetes Conversation Maps, PA Governor’s Chronic Care Initiative and their Coaches, Nutrition Education tools from various vendors, group/team ideas etc.
- Used the ADA evidence based library in developing the PCMH model for care for Louisiana.

Demonstration /Pilot Projects

Many PCMH models are in place across the country. A variety of groups, including payer groups, state medical boards, state and federal government agencies, and national medical
associations have collaborated to develop local PCMH models. Most models are initiated as
demonstration projects to assess the program’s impact and cost-savings on a particular patient
group, and in some cases the model targets specific disease conditions.

Numerous groups have developed resources that describe their PCMH models. The following
PCMH information describes resources from key leaders in this subject area.

- The Blue Cross Blue Shield (BCBS) National Association reports 32 PCMH models are
  in place or under development (Appendix J).

- Patient Centered Primary Care Collaborative showcase active PCMH demonstrations on
  their Web page (http://www.pcpcc.net/content/pcpcc-pilot-projects).

- NCQA has developed a PPC-PCMH (PPC-PCMH) recognition program that “recognizes
  physician practices functioning as PCMHs by using systematic, patient-centered and
  coordinated care management processes.” The NCQA Standards and Guidelines for
  Physician Practice Connections© are available at: https://inetshop01.pub.ncqa.org/publications/product.asp?dept_id=2&pf_id=30004-301-08

  individuals to find doctors who have demonstrated that they meet important standards of
  care, such as the PPC-PCMH.

- The American Academy of Family Practitioners (AAFP) physician resources are

- The American Academy of Pediatrics (AAP) has a sophisticated Web page that facilitates
  viewers’ access to information on PCMHs by state: (http://www.medicalhomeinfo.org/model/map.html).

- The American College of Physician’s (ACP) Web page includes a list of active
  demonstration projects at: http://www.acponline.org/running_practice/pcmh/.

- In 2010 through 2012, the Centers for Medicare & Medicaid Services will conduct
  demonstrations projects in up to eight states encompassing about 400 medical practices,
  2,000 physicians, and 400,000 Medicare beneficiaries. Information about the Medicare

Case for Registered Dietitian Participation in PCMH

Since medical home tenets include disease prevention and management of co-morbidities, RD
participation is essential to improve patient health outcomes and reduce costs. Based on the
medical home workgroup’s limited survey results, the majority of RDs who reported participation indicated that it was in response to their employers’ request. While this approach may be beneficial for RDs employed in large healthcare networks, other RDs must take a more proactive approach if their role is to be fully recognized and funded by the PCMH. Currently, overall RD experience with PCMH appears to be minimal. This may be the result of many RDs’ apparent lack of awareness of PCMH and the impact of healthcare regulations on their practice, PCMH financial limitations, or uneven geographic distribution of medical home facilities. RDs must take action to address these barriers and to advocate for RDs services in the PCMH. The following strategic plan encourages RDs to increase their involvement in the PCMH at the grassroots level.

**Strategic Plan**

The ADA Medical Home Workgroup suggests the following goals, strategies and tactics as the Association addresses RD participation in PCMH activities. An assessment of staffing and funding requirements to support the activities, prior to initiation of any recommendations must be completed with a final decision-making outline of tactics.

**Goal One**

Current and future RDs are empowered to advocate for inclusion in the patient centered PCMH and other health care models as the preferred provider for food and nutrition services.

**Strategy #1: ADA provides resources to enhance RDs knowledge, skills and involvement as proactive participants in the PCMH.**

**Tactics**

- ADA develops focused message(s) and/or an official position on the RDs role in the PCMHs.
- ADA participates in stakeholder coalitions addressing the PCMH and other health care models at the national level to identify best practices for RD involvement. For example:
  - Involvement in the Patient-Centered Primary Care Collaborative (PCPCC).
  - Create PCMH resource page on ADA Web site:
    - (Preferred formats include educational Webinars, position papers, RD promotional materials, self-learning modules, electronic and print newsletter articles. Other resources could include podcasts, flash presentation on Web, House of Delegates meeting, FNCE, state meetings, etc.)
    - Create a repository of existing resources for RDs related to the PCMH (i.e. PNPG DPG newsletter article, Nationwide Nutrition Network inclusion).

**Strategy #2: Support the activities of state affiliates and ADA dietetics practice groups to promote the RD’s role in PCMH.**
**Tactics**

- Encourage inclusion of PCMH goals, as stated the focused message and/or position statement (Strategy 1, Tactic 1), in the affiliate and DPG strategic plans.
- Facilitate development of the PCMH web page on affiliate and DPG Web sites.
- Promote newsletter articles on RD involvement in the PCMH to affiliates and DPGs for use in quarterly newsletter articles (Appendix I).
- Encourage affiliate collaboration on PCMH initiative activities (e.g., electronic listserv and social networking).
- Showcase to current affiliate and DPG leaders successful affiliate and DPG activities and models (i.e., PNPG DPG).
- Develop affiliate and DPG-targeted presentation/speaker’s bureau for on topic showcasing successful RDs.

**Strategy #3:** Understand federal, state, and local government pending legislation, law and regulations related to the patient-centered PCMH.

**Tactics**

- Applicable ADA Committees (e.g., LPPC, Quality Management, and Coding & Coverage) and the ADA taskforce on healthcare reform have a PCMH expert to assist with ADA programming related to the PCMH. If PCMH movement gains momentum, a separate national PCMH committee (similar to the Coding & Coverage physician workgroup) should be formed.
- Affiliate reimbursement representatives list and monitor local payer’s involvement in PCMH program development. Provide updates to ADA Coding & Coverage team.
- Affiliate State Policy Representatives (SPR) list and monitor local legislation for PCMH.
- ADAPAC provides support to candidates for public office who support RD involvement in PCMH.
- In states with active and pending medical-homes demonstrations/pilot programs, affiliates identify PCMH expert who becomes affiliate member advocate for involvement in RD inclusion in the medical-home. An ADA staff lead will be identified to support volunteer leader.
- Integrate dietetics students in the legislative process and proactively involve students by supporting the ADA efforts toward this initiative.
- ADA to provide link to National Academy for State Health Policy (NASHP).
- Affiliate newsletters include one article on how to follow medical-home and emerging delivery systems legislation.
- Address in 2010 Public Policy Workshop (PPW) and affiliate legislative days.

**Strategy #4:** Incorporate the PCMH model in all applicable aspects of dietetics education programs to prepare students for participation in patient-centered medical homes.
Tactics

- Identify, and create case studies and presentations to facilitate educator integration of the PCMH model information in CADE accredited program curriculums that prepare future RDs.
- Integrate the PCMH with the Nutrition Care Process (NCP) by developing learning activities that illustrate how to use the NCP in this model of care.
- Develop dietetic students skills regarding PCMH in the professional practice area by incorporating concepts that apply to required CADE standards and competencies [e.g., Coordinated Programs (CP-2.11), Didactic Internship (DI-2.11)].

Goal Two

The PCMH providers value and choose RDs as preferred providers for food and nutrition services.

**Strategy #1: Demonstrate the value of RD participation in the PCMH provider community.**

Tactics

- Customize Evidence Analysis Library (EAL) RD effectiveness data messages for PCMH providers.
- Develop PCMH provider targeted materials that promote the use of the RD.
- Create a public resource Web page on ADA Web site for PCMH providers.
- Develop toolkit(s) that empower RDs to promote their services in PCMH (e.g., Power-Point presentation on the value of an RD, inserts from the MNT Works Kit).

**Strategy #2: Encourage the PCMH provider community to adopt RD participation in the PCMH.**

Tactics

- Complete alliance scan – identify existing alliance relationships to leverage and new alliances that need to be created. Encourage affiliates and DPGs to do likewise.
- Participate in stakeholder coalitions addressing the PCMH and other health care models at the national level to identify and promote PCMHs with RD participation.
  - Involvement in the Collaborative (PCPCC).
  - Position the role of the RD in PCMHs with other groups (i.e. NCQA, AMA, AAP, AAFP etc.)
  - Pursue recognition of nutrition services as standard in the NCQA Medical Home Recognition program (Appendix b)
- Develop marketing plan for Nationwide Nutrition Network as a resource for identifying local RDs.
- Establish a presence at the national and state level in key primary care physician venues where RDs can showcase their services (i.e. NPCP conference).
References


(2) Institute of Medicine (U.S.) and Donaldson M. Primary care: America’s health in a new era. Washington, DC. National Academy Press. 1996.


Appendices:


Appendix F  Carlson ES. ANA Fights for Inclusion of Nurse Practitioners in PCMHs. Amer Nurse Today. 2008 6(4).

Appendix G  Carlson ES. Nurse Practitioners should be eligible to serve as “PCMHs” for primary care. Amer Nurse Today. July 2008:15.


Appendix J  Patient-Centered Medical Home Demonstrations. Blue Cross Blue Shield Plan Pilots (as of March 2009)

**Note:** Appendices are not included in the Health Reform Backgrounder due to extensive page length. If you would like a copy of any of the appendices, please contact HOD@eatright.org.
Building Block

Medical Home: Focus On Nutrition Services in the Community

Kate Orville, MPH
Co-Director, Washington State Medical Home Leadership Network

Betty Lucas, MPH, RD, CD
Lecturer, Family and Child Nursing, Nutritionist

Katherine Tekolste, MD
Clinical Associate Professor, Pediatrics, Developmental Pediatrician, Center on Human Development and Disability
University of Washington, Seattle, Washington 98195-7920

The term “medical home” originated from the American Academy of Pediatrics (AAP) in an effort to help families of children with special health care needs receive better coordinated care for their children. This concept has evolved with the goal of using a team approach to help the family manage their child’s complex issues. The AAP defines a medical home as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally-effective (1). A medical home can be a physician’s office, a hospital outpatient clinic, a community health center or school-based clinic, as long as it provides the services that constitute comprehensive care. In a medical home the child or youth, his or her family, primary care provider (PCP) and other health professionals develop a trusting partnership based on mutual responsibility and respect for each other’s expertise. Together, families, health care professionals and community service providers identify and access all medical and non-medical services needed to help the child and family. Through this partnership, the family/patient can access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family. Table 1 describes the important collaborators in providing a medical home for an individual.

Registered dietitians (RDs) are members of the health care team of any child for whom they provide services, with or without special needs. Communication and coordination with the medical home team members are important principles to integrate into all health care practices, including dietetic practices.

How do medical homes help support families and children? As an example, Jeremy is two years old and has multiple health concerns including asthma and a history of poor growth due to his prematurity (born at 28 weeks gestation). When Jeremy was an infant his parents felt that few resources were available to them for Jeremy’s care and they obtained conflicting advice about his care. As Jeremy’s PCP and parents worked together to provide a medical home for Jeremy, his parents developed a sense of confi-
From the Editor

In this issue of the Building Block we are continuing to highlight the Maternal and Child Health initiatives that affect all of us in our clinical practice. This issue of the 2006-2007 year is focused on the medical home initiative. Remaining initiatives—Bright Futures, Genetics, and Cultural Competency—will be the focus of subsequent issues of the Building Block.

In the lead article for this medical home issue, Kate Orville, Betty Lucas, and Katherine TeKolste define the medical home concept, describe key medical home partners including the role for RDs, and provide insight and strategies for joining a medical home team. The evidence-base for the medical home concept is presented in a series of annotated research articles; individual state medical home programs and activities are offered as an overview of medical home activities, and specific nutrition resources which are effective medical home tools are described.

Transition from pediatric to adult health care is an important medical home activity and this is reflected in the article reprinted from Nutrition Focus "Passing the Baton: Nutrition and Transition to Adulthood for Youth using Enteral Nutrition". Cam Lanier effectively uses a case report to remind us of the preparation, education, support, and health care and community strategies necessary to foster effective transition to adult-based care. She provides useful guidelines; for example, Table 1 is entitled “Family Questions” and guides the provider through a series of questions that prompt families to consider important aspects of nutrition services during and post-transition to adult care.

Research to examine the efficacy of the medical home concept is presented in the reprinted article by Gail Kieckhefer et al. The article examines the presence of medical home characteristics and describes the relationships between medical home and health services utilization in a national sample of children with asthma. In this report a medical home is represented in three ways: 1) the presence of a usual source of care, 2) identification of a specific person as the usual source of care, and 3) an index of medical home characteristics. In summary, parents are most satisfied with a usual source of care and children and youth with asthma benefit from having a usual source of care, but not necessarily a specific person to provide that care. RDs often provide a usual source of care or ‘usual source of supportive information for families; this article demonstrates the medical home concept in supporting a ‘usual’ provider presence for families.

Betty Lucas, MPH, RD, CD received the Excellence in Practice Award for Community Dietetics at FNCE this fall. We are pleased to provide a short biographical sketch of her professional activities which explicitly support nutrition services for families whose children have special health care needs.

Cristine M Trahms, MS, RD, FADA
2006-2007 Editor, Building Block for Life

Paula Charuhas, MS, RD, FADA, CNSD
2006-2007, Co-editor, Building Block for Life

A special thanks to the reviewers for this issue of the Building Block:

Mimi Kaufman, MPH, RD, LD
Early Intervention Dietitian, PRIDE ECI Program,
Round Rock, TX

Malai Holland, MPH, RD
CSHN State Nutritionist, Vermont Dept of Health
Research Associate, Center for Disability and Community Inclusion (UCEED)
University of Vermont, Burlington, VT

Sandi Laney, RD, CD
Children with Special Health Care Needs Nutritionist
Spokane Regional Health District
Spokane, WA

with special health care needs report experiencing an improved relationship with their primary care providers, missing fewer days at work and having an easier time obtaining letters of medical necessity and referrals to specialists. Parents also feel they are better able to understand their child’s condition, get medical prescriptions filled and telephone calls returned. Most importantly, parents indicated that they also learn how to access
resources and set goals for their child. Their children experienced decreased rates of hospitalization (5). The savings on reduced hospitalizations results in a savings of $10.50 for every $1.00 invested (6). Table 3 describes the benefits of a medical home to families and their children.

RDs and the Medical Home

The medical home approach recognizes that it takes a team to provide comprehensive care to children, especially those with special needs. The primary care provider has the responsibility of helping the child and family identify needs, access resources, and integrate/understand the separate components of a child’s health care plan. Medical home providers are expected to share “clear and unbiased information with the family about the child’s medical care and management and the specialty and community services and organizations they can access” (1). The medical home also addresses care coordination services “in which the family, the physician, and other service providers work to implement a specific care plan as an organized team” (7).

Nutrition is important

The Medical Home Policy Statement calls for comprehensive health care that includes a number of nutrition-related services: “provision of primary care, including but not restricted to acute and chronic care and preventive services, including breastfeeding promotion and management, immunizations, growth and developmental assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, nutrition, safety, parenting and psychosocial issues” (7).

Primary care providers see the need for RDs

While physicians believe that nutrition is important in the care of their patients, they feel inadequately trained to provide optimal nutrition counseling (8). Most graduating medical students rate their nutrition preparation as inadequate (9). PCPs often provide nutrition information either themselves, through clinic staff, or through referral to and collaboration with RDs.

Parents see the need for RDs

Families are also interested in nutrition but generally feel they do not have enough knowledge in this area. Parents with nutrition-related questions will ask their child’s PCP and/or use the internet to try to find answers. One study found 74% of parents with access to the internet used it to find health information for themselves or their family. Nutrition and exercise were the third most frequent topics of interest, following disease-specific and medication information (10). According to a survey on unmet health care needs for children with special health care needs are at increased risk for nutritional counseling services available to them (11). Providing topical, family-centered nutrition services is an explicit opportunity for RDs on the medical home team.

Children have a need for RDs

Children with special health care needs are at increased risk for nutrition-related problems. It has been estimated that up to 40% of these children have nutrition risk factors that could be helped by referral to an RD (12).

Some of the common nutrition problems and reasons for referral to an RD include:

- Delayed growth, underweight and overweight
- Feeding delays, oral-motor problems, or altered feeding interactions

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Table 1. Who is part of a Medical Home?

- Child/youth
- Family
- Primary care physician and office staff
- Allied health professionals—e.g., registered dietitian, physical therapist, occupational therapist, speech and language therapist, children with special health care needs nurse, pharmacist, medical supply company, mental health provider.
- Family’s community
- Community programs and organizations—e.g., youth sports, community center, community pools, religious institutions,
- Pediatric specialists, when needed
- Pediatric or family dentist
- Education services—e.g., for children who require modified foods, oral supplements, or tube feedings at school

Adapted from the National AAP Medical Home Initiative (1)

Table 2: Critical Goals for Health Care of Children with Special Health Care Needs, 2010

1) Children will be screened early and continuously for special health care needs.
2) Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.
3) Children with special health care needs will receive regular ongoing comprehensive care within a medical home.
4) Families of children with special health care needs will have adequate public and/or private insurance to pay for the services they need.
5) Community-based service systems will be organized so families can use them easily.
6) Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life.

Adapted from: http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm
Who are the Children with Special Health Care Needs?

‘Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.’

Nationally, it is estimated that about 18% of children have a special health care need. Chronic health conditions, (e.g., asthma and diabetes), and disabilities (e.g., spina bifida, cerebral palsy, autism) range from mild to severe. Eight percent of children have a current health problem that is felt to be moderate or severe in nature. Nine percent of children ages 3 to 17 have moderate to severe emotional, behavioral or concentration or social interaction difficulties.

Some groups of children are at extra risk: children in foster care have a high incidence of developmental and mental health/behavioral problems; and children of low birthweight experience an increased prevalence of disability such as cerebral palsy, cognitive impairment, or sensory impairments. These children have a higher incidence of feeding difficulties and gastroesophageal reflux than infants who are born at term.

Adapted from: ‘Definition of Children with Special Health Care Needs at http://www.medicalhomeinfo.org/about/def_cshcn.html

Inadequate or excessive diet quantity or quality
• Medication/nutrient interactions
• Elimination problems, i.e., constipation, diarrhea
• Altered energy and nutrient needs, e.g., inborn errors of metabolism
• Dental caries including early childhood caries that may be related to inappropriate breastfeeding or bottle-feeding
• Poor or excessive appetite
• Poor parent-child feeding relationship
• Limited access to nutritious, healthy food

The RD’s Role in the Medical Home:

RDs are important members of the medical home team and nutrition is an important component of prevention and management of chronic diseases. The American Dietetic Association (ADA) supports nutrition services as “essential components of comprehensive care for infants, children, and adults with developmental disabilities and special health care needs” (12). RDs have both unique assessment skills and team skills to bring to bear for the medical home team. The medical home team is of greatest benefit to families when all aspects of the child’s needs are expertly assessed and coordinated. To provide high quality, effective care that meets the needs of the child and family, team members must communicate and coordinate with each other by effectively sharing information and key management components.

Families need written information about diagnoses and treatment plans. An RD can develop a nutrition care plan that is culturally sensitive and comprehensive and works for the family. The plan should address nutritional needs from the perspective of the child/youth and the family and it should also include referrals and resources that can help the family implement the plan. For example, if the child is eligible for the WIC program and for some reason is not enrolled, the RD should help the family start the enrollment process. If the child requires a modified school meal, then the RD should help assure that this occurs. Standardizing the format of a nutrition care plan and sending it to the PCP have been identified as strategies that improve communication and forge partnership between RDs and physicians (13).

Appropriate nutrition information resources may provide an important link to families other health care providers, and RDs working with children with special needs. Examples of nutrition resources include the Bright Futures: Nutrition Materials (14), Nutrition Interventions for Children with Special Health Care Needs (15), and Children with Special Health Care Needs: Nutrition Care Handbook (16).

Connecting RDs and PCPs in Your Community

Families and health care providers may not be aware of nutritional health resources in their local area. For example, in the state of Washington, the resource guide Getting Connected: Prevention and Primary Care for Young Children with Special Health Care Needs, outlines nutrition risks, screening procedures and nutrition referral locations in Washington State (17). Washington State also has Community Feeding Teams that provide an interdisciplinary approach to complex feeding problems in a comprehensive, cost-effective manner (17). Other states may have similar nutrition resource information.

The following case report illustrates the role of the medical home and the importance of connecting and collaborating with health care providers in the community.

Jonas is a 10-month old (corrected age) boy who was born at 28 weeks gestation and required initial nasogastric tube feeding due to hypotonia and poor suck. At the time of discharge from the hospital neonatal intensive care unit (NICU) he was receiving pumped breast milk. Infant formula was later added. NICU discharge plans included referrals for an early intervention (EI) program and continued participation in the Women, Infants and Children (WIC) program. This plan was communicated to the PCP.

Since discharge, Jonas’s weight gain has been minimal and fluctuating; he is seen frequently by his PCP. The PCP communicates with the WIC nutritionist regarding current growth parameters and feeding. Jonas’ parents continue to report feeding difficulties, including irritability and slow feeding. They report feeling anxious about the need to “get him to eat.” The PCP made a referral to a pediatric gastroenterologist to assess for the
possibility of gastrointestinal reflux (GER) or other gastrointestinal (GI) concerns. She also made a referral to a community feeding team for an interdisciplinary feeding evaluation. After the feeding team evaluation the PCP was provided with a report that documented the current concerns, feeding history, and other services provided. The PCP made an appointment with the family to discuss the results of the evaluations. Family permission is requested to share these results with the feeding team and EI program to ensure that Jonas’s health care providers are informed and supportive of the family and Jonas’s therapy and progress.

RDs, PCPs, and families all share the common goal for family-centered and coordinated services. As an RD, introducing your skills and interests to the health care provider community, to group (e.g., hospital staff meetings) or to individual settings (e.g., practice site visits) is a start. Ongoing communication is important and leads to greater satisfaction for all parties—RD, child and family, and PCP. The medical home model of care is an excellent way for everyone to share ideas and plans for the child and family. Since feeding and eating is a basic life function, nutrition services should be a part of this team.

### Barriers

Unfortunately, there are barriers that may make it difficult for community service providers and PCPs to collaborate. These barriers may include inadequate financing to coordinate care (care coordination can be very time consuming and is typically not reimbursable; nutrition services may not be covered by insurance), PCPs may lack knowledge about community services (both what these services do and how to access them), and there may be a general lack of awareness on the part of both PCPs and community service providers about each other’s professional cultures and how best to work together.

### Resources

However, if RDs market themselves, PCPs are more likely to refer if they:

- Know you and your skill set
- Know how to refer to you
- Are provided assessment reports and information about patients they have referred
- Hear positive comments from shared patients and their families

In Washington State a template was developed for RDs to use in compiling the local nutrition resources and contact information in a single document (17). The target audience includes PCPs, office staff, early intervention programs, public health agencies, and dietetic associations. It can be adapted and updated to reflect the community, and can be used for in-services, conferences, meetings, and other outreach activities.

Some excellent strategies and tips for how professionals can work together and the basic steps for collaboration to strengthen community services have been developed. See “Strengthening the Community System of Care for Children and Youth with Special Health Care Needs and Their Families: Collaboration Between Health Care and Community Service Systems” (18) and “Connecting With Primary Care Providers: Outreach Tips for Nutrition Service Providers” (19) in the references below.

### References


### Table 3. Benefits of the Medical Home

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<th>Benefits of the Medical Home</th>
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<tr>
<td>• Efficient use of limited resources</td>
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<tr>
<td>• Reduced hospitalizations and length of stay</td>
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<td>• Reduced utilization of the emergency department</td>
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<td>• Decreased caregiver strain and parental missed days from work</td>
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<td>• Decreased school absences</td>
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<td>• Increased opportunities for outcomes-based clinical improvement</td>
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<td>• Decreased school absences</td>
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<td>• Increased coordination of care</td>
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<td>• Establishment of a forum for problem-solving</td>
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<td>• Equity/reduction of disparities in health between socially advantaged and disadvantaged populations</td>
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<tr>
<td>• Improved coordination of care</td>
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Adapted from Palfrey, et al., 2004 and Liptak, et al., 1998.
Evidencc-base for the Medical Home in Practice

The evidence-base for the medical home initiative is highlighted in the following annotated articles. These research articles demonstrate the need for partnerships to 1) provide family-centered nutrition assessment and education, 2) promote communication among providers, and 3) promote early intervention for vulnerable children.

Physicians Request Breastfeeding Education


Physicians (n=262) were surveyed about their breastfeeding promotion practices, knowledge, and areas in which they need more information to be more influential with patients in the initiation and duration of breastfeeding. Over half of the physicians (51%) reported no or limited education in breastfeeding, whereas only 9% reported adequate education. A knowledge assessment indicated almost half (42%) did not know certain viruses could be transmitted through breast milk. There were also mixed responses to the need for vitamin D supplementation. Promotion practices included most (82%) believing the physician has a primary role in the breastfeeding decision, and most physicians did discuss the benefits with patients. The main area physicians reported needing more education was problem-solving. Partnerships with RDs may fill the gaps in the support needed to increase rates of breastfeeding.

Promoting Nutrition Consultation in the Community


The program objective was to integrate RDs into the offices of 80 family physicians. In collaboration with physicians, RDs assessed, treated, and consulted on a variety of nutrition-related problems. A central management team coordinated the RDs’ activities. The RDs regularly visited family practices for consultations with both patients and physicians. Patients had better access to nutrition services provided in familiar settings. Family doctors learned about dietary counseling through direct feedback from RDs. Patients, RDs, and family physicians reported great satisfaction with this model.

Improving Communication with Community Physicians


Mailed surveys were used to elicit aspects of outpatient communication between RDs and PCPs. Samples of correspondence were also evaluated.

Barriers to Successful Nutrition Counseling by PCPs and Opportunities for RDs


A survey was conducted to assess disparities between physicians’ beliefs about the importance of nutrition counseling and practice. Over 1,000 PCPs responded to the survey. Over two-thirds of PCPs provided counseling to less than 40% of patients and spent fewer than five minutes at this activity. PCPs ranked perceived barriers to delivery of dietary counseling as lack of time, patient noncompliance, inadequate teaching materials, lack of counseling training, lack of knowledge, inadequate reimbursement, and low physician confidence in providing accurate nutrition information.

Role of the Medical Home in Early Identification of Children with Special Health Care Needs


Early identification of developmental disorders is critical to the well-being of children and their families. Early identification is an integral function...
of the primary care medical home and an appropriate responsibility of all pediatric health professionals. This important article provides an algorithm to support health care professionals in developing a pattern and practice for addressing developmental concerns in children birth to age three years. An abbreviated list of recommendations for the medical home for children with special health care needs include: 1) performing developmental surveillance at every preventive visit; 2) administering standardized developmental screening tools for all children, even those who appear to be at low risk; 3) scheduling early return visits for children for whom surveillance raises concerns; 4) referring these children; 5) coordinating developmental and medical evaluations for children with developmental concerns; 6) initiating a program of chronic condition management; 7) documenting all surveillance, evaluation, and referral activities; 8) establishing working relationships with programs, services and resources; and 9) using a quality improvement model to integrate surveillance and screening into practice.

**Important Components to Achieving Family and Provider Partnerships**


A major principle of family-centered care is a strong partnership between families and providers working together to provide comprehensive care and related services. A telephone survey of caregivers of nearly 39,000 children with special health care needs was conducted to assess partnership outcomes and socioeconomic and demographic influences. More than 85% of families reported usually or always feeling like a partner in their child’s care. Living in poverty, minority racial and ethnic status, absence of health insurance, and depressed functional ability place children and their families at elevated risk of being without a sense of partnership. A sense of family partnership was associated with improved outcomes for the child.

**Does a Medical Home Save Health Care Dollars?**


This study evaluated the impact of having a medical home on outpatient costs of children and youth with special health care needs in Iowa. The data for over 1,100 children aged 6 months to 12 years was evaluated. For all Medicaid-enrolled children, outpatient costs were higher for children with special health care needs. The degree of ‘medical homeness’ was not related to outpatient costs for children and youth with special health care needs. It is postulated that having a medical home may affect inpatient costs more than outpatient costs for children and youth with special health care needs. However, this will require further investigation.

**State Medical Home Nutrition Resources**

The national medical home website, provides information about medical home resources, tools kits, and programs. On this website each state has its own medical home activities page. To check on the medical home activities in your state, visit [http://www.medicalhomeinfo.org/](http://www.medicalhomeinfo.org/), then click on your state on the map. The medical home activities of three states are highlighted here: Washington, Vermont, and Texas. The following information is adapted from the state medical home websites.

**Washington State**

The Washington State Medical Home Leadership Network at [http://www.medicalhome.org/about/medhomeplan.cfm](http://www.medicalhome.org/about/medhomeplan.cfm) also contains the Washington State Medical Home Nutrition Resources Page [www.medicalhome.org/resources/nutrition.cfm](http://www.medicalhome.org/resources/nutrition.cfm)

The Medical Home Leadership Network (MHLN) is a network of volunteer parent-professional community medical home teams. These MHLN teams do not provide direct care to children, but they work to identify unmet medical home needs in their county, and carry out activities to address these needs. Each team includes a minimum of a pediatrician or family physician, a parent of a child with special needs, a public health nurse (usually the Children with Special Health Care Needs Coordinator), and an early intervention family resources coordinator (FRC). There are currently 21 teams covering 25 of the state’s 39 counties and the majority of the state’s population.

Since community-based PCPs may not be aware of the nutrition providers in their area from different settings, RDs can improve communication and collaboration with MHLN teams and other PCPs by sharing screening and referral tools, clarifying their nutrition role and the eligibility of children served within their settings, and providing a system of follow-up communication after accepting a nutrition referral.

The CSHCN Nutrition Network is a group of RDs who provide nutrition services for children with special health care needs. They receive training at the Center on Human Development and Disability, University of Washington, and participate in two annual continuing education events. Currently about 90 RDs in Washington belong to the CSHCN Nutrition Network, and work in a variety of employment settings, including WIC, local health departments, community clinics, hospitals, early intervention centers, schools, and home health agencies. See: [http://depts.washington.edu/cshcnut/cshcn_nut_net.html](http://depts.washington.edu/cshcnut/cshcn_nut_net.html)

**Washington State Community Feeding Teams** provide an interdisciplinary approach to address feeding/
nutrition concerns for children in a comprehensive, cost-effective manner. The teams include a minimum of a feeding therapist (occupational therapist or speech therapist), an RD, and a specialist in behavior/family interaction (nurse, social worker, behavior therapist). Feeding teams work directly with families and PCPs to help parents/caregivers resolve important issues related to feeding and nutrition. The team approach can benefit a family by avoiding duplication of services and allow all the nutrition and feeding to be addressed by one team. In most cases, these community-feeding teams also provide intervention and follow-up.

The approximately 15 feeding teams in Washington have been formed as either interagency or intra-agency teams. Agencies that have been involved include local health departments, developmental centers, school and education service districts, hospitals and others, depending on the community resources. See: http://depts.washington.edu/cshcnnut/feeding_teams_list.html


**Vermont**

The Vermont Medical Home projects are listed at: http://www.medicalhomeinfo.org/states/state/vermont.html#med

In Vermont, the Vermont Department of Health, Children with Special Health Care Needs Program has a network of community-based RDs who act as consultants and are available to provide nutrition services for children and families. The consultants are paid through state Title V and Part C funding for children who are eligible for the programs. The RDs often make home or school visits and attend team meetings at home, school or physician’s office as part of the Medical Home project. The RD consultants in this network, like Washington State, also receive regular in-service training and are employed in various other nutrition related positions in the state.

**The Medical Home Learning Collaborative** is a project committed to helping primary care practices become accessible, family-centered, and provide care that is continuous, comprehensive, coordinated, compassionate, and culturally effective. A particular emphasis is placed on care and family involvement in decision-making for children with special health care needs.

**Medical Home Learning Collaborative II (MHLC2)** is a program that seeks to improve care for children and youth with special health care needs while fostering relationships between state Title V agencies and primary care practices. The most dramatic outcome results were seen in the decrease in unplanned hospitalizations and emergency department visits. Unplanned hospitalization decreased 13 to 18%. Emergency department visits were reduced overall; one site experienced a 20% reduction.

As a result of participating in the MHLC in 2003-2004, nearly 60% of PCP practices report that they are partnering with families to assess needs, plan care, and set goals. Nearly 70% of PCP practices report improvements in access to providers. Half of the practices maintain a registry of children and youth with special health care needs.

**MCHB Medical Home Grant:**

The purpose of the project was to increase the capacity of pediatric practices throughout Vermont to provide medical home services for children with special health needs. Specific technical assistance and supports for systems changes are used to increase primary care practices’ collaboration with families, specialists, and community resources. Each participating pediatric practice identified children with special health care needs in their practice and assessed their ability to serve families as a medical home. Sustainability will be strengthened by collaboration with Medicaid for funding strategies and by incorporating the work of this project into state planning activities.

**Healthy Tomorrows Partnership for Children Grant: Whatever It Takes**

The purpose of this Vermont grant is to reduce the number of children whose healthy development was at risk by increasing access to a comprehensive medical home. ‘Whatever It Takes’ places social work students and an experienced social work supervisor at community-based offices, where they provide intensive social work services to children and families. As a part of the medical home team, nutrition services are provided for children in need. Family/social work/pediatrician/nutritionist/community partnerships have been developed to ensure that children and families received comprehensive, high quality, coordinated services.

**Texas**

The Texas Medical Home projects are listed at: http://www.medicalhomeinfo.org/states/state/texas.html

**Texas Medical Home Toolkit for Families** provides information for families on the concept of medical home and how to get a medical home organized for children who have special health care needs.

The Texas component of the National Initiative for Child Health Quality (NICHQ) Medical Home Learning Collaborative, was a 15-month project committed to helping primary care practices become accessible, family-centered, and provide care that is continuous, comprehensive, coordinated, compassionate, and culturally effective. A particular emphasis was placed on care coordination and family involvement in decision-making for children with special health care needs.

**Emergency Preparedness for Children with Special Needs**

The Children with Special Health Care Needs (CSHCN) Services
Program of the Texas Department of State Health Services recently published a bilingual booklet titled, “Emergency & Disaster Planning for Children with Special Health Care Needs.” The booklet contains a bilingual Emergency Information Form for Children with Special Needs.

**Family-Centered Care Champions Incentive Grant**

The goal of the project was to organize a Parent Group Network designed to promote family-centered care by providing information and support to parent groups at the local level. This includes the identification, production and dissemination of family-centered and practical tools/methods for families to use in order to build partnerships with health care providers that promote both family centered care and effective medical coordination within the medical home.

**Healthy Tomorrows Program for Children Grant 2002-2007:**
Montwood Wellness Center, El; Paso, TX:

The project provides comprehensive pediatric care for children in the Socorro Independent School District area, a community with 38.6% of the population at or below the federal poverty level. This collaboration between Texas Tech University Health Science Center Department of Pediatrics and Socorro Independent School District establishes a medical home for children who face many barriers to access health care.

Program goals include establishing a medical home for children who have no primary care provider; increasing and enhancing each student’s academic potential through health maintenance and education; creating a new system of community support individuals who will work as a link between individual homes, parents, families, and the wellness center; and developing continuous evaluation, feedback, and research based on the results of the program.

**Healthy Tomorrows Program for Children Grant 2005-2010:**
Behavioral Developmental Primary Care Program

Program goals include providing an improved system of behavioral/mental health/developmental screening, assessment, and care coordination for school-aged (3-19 years old) patients; offering an improved, formalized resource to the larger Central Texas community by providing diagnostic assessments, case coordination, and a medical home to youth and families referred specifically to the program by schools, youth serving agencies, and individuals because of behavioral/developmental/mental health concerns.

**Medical Home Nutrition Resources**

These resources, available on the internet, provide useful toolkits, assessment guidelines, and intervention guidelines for effective family-centered medical home nutrition activities.

- **Bright Futures in Practice: Nutrition**
  This nutrition guide provides developmentally appropriate nutrition supervision guidelines for children from birth to adolescence, describes the role of health professionals in delivering nutrition services within the community and encourages partnerships among families and health professionals. See: www.brightfutures.org/nutrition/

- **Nutrition Interventions for Children with Special Health Care Needs—A Self Study Curriculum and A Nutrition and Oral Health—Self Study Curriculum**
  Developed by the Pacific West MCH Distance Learning Network and designed for RDs and other health care professionals who see children with special health care needs as part of their clinical practices. The curriculum consists of several modules; each approved for one CEU from the ADA/CDR. Available at [www.pacificwestmch.org](http://www.pacificwestmch.org)

**The Medical Home In Action**

The following two articles, reprinted and adapted with permission of each publisher, highlight two medical home concepts: transition and cost-effectiveness of medical home activities.

The first article “Passing the Baton: Nutrition and Transition to Adulthood for Youth Using Enteral Nutrition” provides insight into the role of the RD during transition from pediatric to adult health care services for youth with special health care needs. The RD has a critical role in assuring that youth remain well nourished and
have access to essential services during this sometimes stressful process for youth, families, and providers.

The second article, “Presence and Characteristics of Medical Home and Health Services Utilization Among Children with Asthma” assess the role of the medical home in assuring high quality health care to children with special health care needs, in this case, asthma. The authors look at utilization of health care services as a measure of the effectiveness of the medical home concept.

Introduction

“Transition” is used to describe the process of moving from youth to adulthood in all areas of life including education, employment, finances, home living, community living, recreation and leisure, personal responsibility and health. The Maternal and Child Health Bureau (MCHB) clearly recognizes the importance of supporting transition. One of six Healthy People 2010 outcome measures for children with special health care needs is “All youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work and independence” (1).

“Health care transition” is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (2). The goal of health care transition is to “maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood” (3).

“It is the position of the American Dietetic Association (ADA) that nutrition services are essential components of comprehensive care for infants, children and adults with developmental disabilities and special health care needs” (4). The goal of nutrition transition is to maximize lifelong nutritional status and health through the provision of high quality, developmentally appropriate nutrition services that continue uninterrupted as the individual moves from adolescence to adulthood. Nutrition transition involves supporting optimal nutrition for the adolescent; making preparations for the future for his/her nutrition care and anticipatory guidance to prevent nutrition problems; and connecting the adolescent and family with nutrition services and supports in the adult health care system. Nutrition transition also involves the gradual process of young adults, as cognitively able, to take charge of their health and nutrition; parents gradually letting go of this responsibility; and RDs and other health care providers supporting this process.

Youth with special health care needs using enteral nutrition are defined as those youth receiving the nutrients into the gastrointestinal tract through a tube feeding when oral intake is inadequate (5). Tube feeding may be necessary for a variety of reasons including dysphagia, aspiration pneumonia, or the inability to orally consume enough energy to maintain nutritional status. Tube feeding requires ongoing monitoring and assessment to ensure continued maintenance of nutritional status, especially as conditions change for an individual.

JoAnna’s story highlights barriers to and strategies for transition for youth with special health care needs.

Currently, JoAnna is a 22-year-old woman with a primary diagnosis of...