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"Declaration for Independence: A Call to Transform Health and Long Term Services for Seniors and People with Disabilities" [2009]

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DECLARATION FOR INDEPENDENCE

A Call to Transform Health and Long Term Services for Seniors
and People with Disabilities

**The National Advisory Board on Improving Health Care Services
for Seniors and People with Disabilities**

www.declarationforindependence.org

www.mydfi.org

**Declaration for Independence:
A Call to Transform Health and Long Term Services for Seniors and
People with Disabilities
General Talking Points for All Audiences**

OVERVIEW:

The White Paper is a Call to Action to transform and modernize our health care system:

- Focused on addressing the long-term needs for people with disabilities and those who are aging
- Produced by the National Advisory Board on Improving Health Care Services for Seniors and People with Disabilities (NAB)
 - Sponsored by a Company in this industry, but the intention is to produce a document without any filter
- Change will result as we all further the following **6 Foundational Principles:**
 - 1) Enhance Self-Care through Improved Coordination
 - 2) Encourage Community Integration and Involvement
 - 3) Expand Accessibility of Services and Supports
 - 4) Uphold Personal Preference
 - 5) Empower People to Participate in the Economic Mainstream
 - 6) Invest in Improved Technology

**For supporting details and recommended action on each of the 6 Foundational Principles, please see the White Paper or the supporting powerpoint presentation.*

THE NEED:

Aging in place and independence are not only economically sound courses of action, they are also the preference of the individuals involved.

- Seniors over age 65 fear placement in a nursing home and loss of independence more than death
- 89% of seniors want to age in place
- 87% of people with disabilities who are age 50 and older prefer to live in their own homes
- **Nearly 3 seniors and/or people with disabilities can receive services in the community for the same cost of providing assistance in a nursing facility**

We must act now.

- By 2030, the number of people age 65 and older will double
- From a health and financial perspective, this affects all of us

WHO WE ARE:

The National Advisory Board would like to thank AMERIGROUP Corporation for funding the work on this project.

- **Background:** Drawing from a wide range of distinguished community advocates and healthcare experts, AMERIGROUP in 2007 formed a National Advisory Board devoted to services for seniors and people with disabilities who rely on publicly-funded healthcare.
 - The site www.declarationforindependence.org is devoted to the NAB and the White Paper they have produced.

WHAT'S NEXT:

On Thursday, May 21, 2009, we will be hosting a “Day of Dialogue” in Washington, D.C. Comprised of:

- MORNING -- 1:1 Sit-Downs with key stakeholders (Hill staffers, associations, think tanks, advocacy groups and relevant media/trade publications)
- AFTERNOON -- **Virtual Town Hall Meeting:** Online webinar welcoming above constituencies (and more) nationwide

To learn more and help us change health care for the better, go to www.declarationforindependence.org or www.mydfi.org

- Download the full paper
- Join our Day of Dialogue Virtual Town Hall Meeting on Thursday, May 21, 2009

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DECLARATION FOR INDEPENDENCE

A Call to Transform Health and Long Term Services for Seniors and People with Disabilities

Declaration for Independence is a special report produced by the National Advisory Board (NAB). In issuing this report, we call on the principles below to promote independent living and reform our system of care.

SIX PRINCIPLES NECESSARY TO MODERNIZE OUR HEALTH CARE INFRASTRUCTURE

1. Enhance Self-Care through Improved Coordination

- Transform America's health care system from one that focuses on episodic illnesses to one that assists individuals in self-managing their whole health, with the support of providers and communities.
- Encourage the fundamental and financial investment in physicians to serve as the medical home for patients.

2. Encourage Community Integration and Involvement

- Coordinate support services, housing, and transportation so people are able to participate in the social, economic, educational, and recreational activities available through community living.
- Promote data integration, continuity, and coordination of services through the use of health information exchange.

3. Expand Accessibility of Services and Supports

- Retool programs and regulations to enable people to access the services they need to live independently without creating financial hardship for the family.

4. Uphold Personal Preference

- Leverage the success of long term service models that promote personal strengths and preferences and preserve dignity of participants.

5. Empower People to Participate in the Economic Mainstream

- Encourage the employment of people with disabilities and seniors by removing disincentives for people to work and redefine antiquated descriptions of disability.

6. Invest in Improved Technology

- Invest resources in the continued development of technology that improves individuals' ability to self-monitor chronic health conditions and live independently.

NATIONAL ADVISORY BOARD — WHO WE ARE

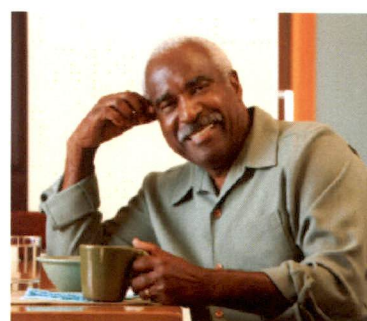
The National Advisory Board on Improving Health Care Services for Seniors and People with Disabilities is composed of distinguished and culturally diverse community advocates, health care experts, and academics who provide guidance and policy recommendations for improving programs and services for seniors and people with disabilities. As a Board, we are people with disabilities; children of aging parents; parents of children and adults with disabilities; and sisters, brothers, spouses, children, and friends of people with disabilities. We represent millions of Americans with disabilities and seniors and their family members, who have struggled with the complexities of our fragmented health care system. Each of us brings a personal perspective to the subject of long term care because each of us has personal experience with it. We, individually and collectively, have worked along with other Americans to overcome the many hurdles to obtain the services we need to live successfully in our communities—hurdles such as the lack of coordination between acute and long term services and supports, antiquated systems and policies, and lack of infrastructure development for long term services.

The National Advisory Board would like to thank AMERIGROUP Corporation for funding the work on this project. AMERIGROUP Corporation, headquartered in Virginia Beach, Virginia, improves health care access and quality for the financially vulnerable, seniors, and people with disabilities by developing innovative managed health services for the public sector. Through its subsidiaries, AMERIGROUP Corporation serves approximately 1.6 million people in Florida, Georgia, Maryland, Nevada, New Jersey, New Mexico, New York, Ohio, Tennessee, Texas, and Virginia.

To learn more — including downloading the full white paper, or joining our online Day of Dialogue on Thursday, May 21, 2009 — please go to www.declarationforindependence.org or www.mydfi.org.

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We believe it is necessary for all Americans to be educated about the issues facing seniors and people with disabilities for two critical reasons. First, the course of aging is a naturally occurring process which affects each of us. Second, no person is impervious to disability: a parent or spouse can become paralyzed as a result of a stroke, an infant can be born with an intellectual disability, a child can become disabled as a result of a playground injury, or a best friend can develop major depression and substance abuse as a result of being a soldier at war. Disability can occur at any time or through the natural process of aging. Disability extends across race, age, ethnicity, level of education, and socioeconomic status. Simply, none of us is immune to aging or living with a disability. Therefore, we believe Americans must be educated on the health, wellness, social, and economic issues facing seniors and persons with disabilities so that we collectively can design a future infrastructure that works and is accessible by all.

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ACKNOWLEDGEMENTS

The National Advisory Board would like to thank AMERIGROUP Corporation for funding the work on this project. We especially thank Nancy Grden, John Littel, Merrill Friedman, and Calise Munoz for their ongoing contributions and review of this paper. AMERIGROUP Corporation, headquartered in Virginia Beach, Virginia, improves health care access and quality for the financially vulnerable, seniors, and people with disabilities by developing innovative managed health services for the public sector. Through its subsidiaries, AMERIGROUP Corporation serves approximately 1.6 million people in Florida, Georgia, Maryland, Nevada, New Jersey, New Mexico, New York, Ohio, Tennessee, Texas, and Virginia.

The National Advisory Board would like to thank Dr. Kim Dunn for her laudable contribution to the content of this paper. We would like to thank those Board members who contributed exceptional time and effort in the development of this paper, including: Mr. Davies, Ms. De La Rosa-Aponte, Ms. Diehl, Dr. Kirschner, Dr. Meiners and Mr. Parker. Most of all, we would like to thank Mr. Frieden for his tireless involvement and direction in this project and Gretchen Thompson of Pinnacle Strategies for the research and writing of this report.

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EXECUTIVE SUMMARY

According to recent statistics, Americans with disabilities and those who are aging are gravely concerned about preserving their independence and freedom.

- Seniors over age 65 fear placement in a nursing home and loss of independence more than death (Prince, 2007).
- Eighty-nine percent of seniors want to age in place; in other words, they want to grow older without having to move from their homes (Prince, 2007).
- Eighty-seven percent of people with disabilities who are age 50 and older prefer to live in their own homes (Kassner et al, 2008).

Many Americans are unaware that few options exist for seniors and people with disabilities who require assistance with daily activities and personal care. It is not until the need for long term services and supports becomes personal that most Americans even begin to experience and recognize the complexities of our nation's health care infrastructure. It is often only then, when individuals have to manage these issues in their own lives, that they find a common theme prevails—***the health care infrastructure is broken.***

The pursuit to provide health care coverage for Medicare and Medicaid beneficiaries has inspired insight on how to transform our fragmented health care system. Our multi-layered health care system is so complex that people are unable to seamlessly transition from one program to another as they age or experience changes in their health care needs. Support programs designed to assist seniors and people with disabilities are fragmented among multiple governmental divisions and payers. Seniors and people with disabilities utilize nearly 67 percent of total Medicaid service dollars—yet, the debate and concern over our nation's health care infrastructure is largely focused on acute care and episodic illnesses. Long term care¹ is often overshadowed by discussions about increased costs for acute health care, prescription drugs, and uninsured persons. While these issues are important, long term services and supports must no longer be overlooked. Instead, long term services and supports must be prioritized and integrated in our health care policy planning and reform initiatives in order to create a high quality, fiscally prudent system that works for all people.

The personal stories presented in this paper provide examples of the many ways in which our current health care infrastructure is crumbling. The fractured foundation of America's health care system will only be further compromised if we as a nation do not appropriately transform the health care system to a modernized infrastructure. Therefore, this *Call to Action* requires each of us—consumers, the medical community, policymakers, program directors, academics, health care organizations, and human service providers—to become active participants in health care transformation activities that yield an improved and modernized health care system. It is the opinion of this National Advisory Board that the modernized health care infrastructure required to meet the needs of people with disabilities and seniors will only come about as others join with us in promoting and furthering the following six foundational principles.

¹ Long term care is a blanket term used for a range of services designed to meet chronic medical, functional, personal and social needs of people with disabilities and seniors. The term "long term services and supports" (LTSS) is also used to refer to services that assist individuals with activities of daily living. LTSS is widely used to emphasize person-centered empowerment. The term "care," used in health care or care coordination, refers to the management of illness and the preservation of health through preventive, assistive, curative, or palliative services that are designed to promote health for individuals or an entire population.

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INTRODUCTION

The pursuit to provide health care coverage to Medicare and Medicaid beneficiaries has stimulated insight on how to transform our fragmented health care system to be more fiscally prudent, while at the same time meeting the needs of our most vulnerable populations—older persons and people with chronic illness and disability. Our nation's multi-layered health care system is in crisis. It is so complex that people are unable to seamlessly transition from one program to another as they age or experience changes in health care needs. Support programs designed to provide assistance are fragmented, making it burdensome for seniors and people with disabilities to access the benefits and supports they require to live independently.

Under the current health system, a child with a disability is eligible to participate in therapeutic and rehabilitative programs and receive adjustments and repairs to her leg braces through school-based programs. However, when she turns 19 years old (age can vary according to state), she no longer qualifies for these same services and she and her family are forced to navigate the health and human service system to locate some other program for which she might qualify. The needs of the child haven't changed but because of the way the system is designed, the assistance ends with her 19th birthday.

Under the current system, when an adult with a disability returns to work and his paycheck breaks the allowable income threshold, he will no longer be eligible for disability assistance and associated acute and long term service benefits. His need for personal care assistance hasn't changed, but according to the way the system is designed, his ability to garner an income above the poverty-level cutoff makes him categorically ineligible to receive assistance.

This paper is not intended to solve all of the ills of our health and social service system. This paper is intended to personalize the subject of long term care and provide education and motivation that will lead to a system-wide transformational shift and, ultimately, will result in a physical, social, and health care environment that works for all people.

LAYING THE GROUNDWORK

A Changing Demographic

In the coming years, the United States will continue to face challenges in providing health care and other social support benefits to its aging population. While there are many factors that increase the cost of health care and social supports, a growing factor in the United States is the aging demographic. 2011 marks the first year where the leading edge of the baby boom generation turns 65 years old. It is estimated that by 2030, the number of people age 65 and older will double (U.S. Census Bureau, 2005). Accordingly, the U.S. economy will feel an unprecedented pinch as these 76 million boomers shift from being working adults, whom we've relied on to pay into federal programs such as Medicare and Social Security, to retirees drawing benefits from the same federal programs. With the average life expectancy rising from 47.3 years in 1900 to 76.9 years in 2000, the aging baby boom generation will require more benefits for a longer period than previous generations (U.S. Census Bureau, 2005).

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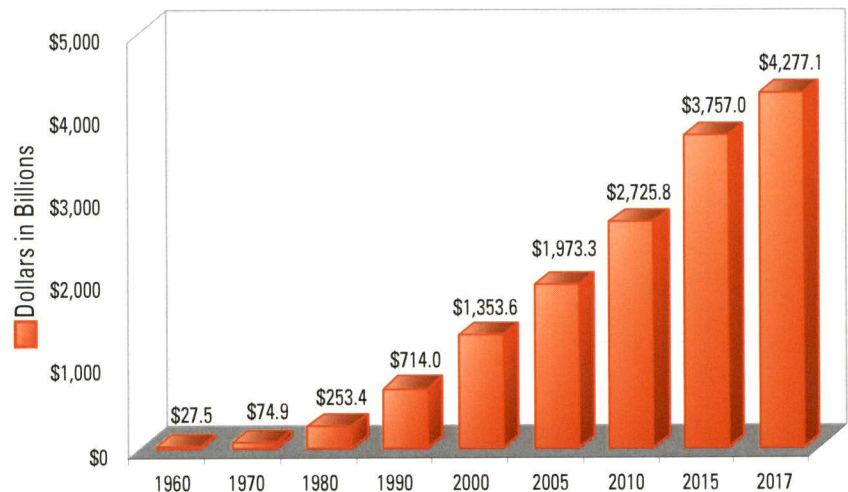
Because modern medicine and technology aid in longer life expectancy, the rate of death from chronic illness and disease has declined. According to recent U.S. Census data, 80 percent of seniors have at least one chronic health condition and 50 percent have at least two. While modern medicine extends the life of our population, health care costs will continue to rise simply because the number of people eligible for benefits will go up and the benefits received by each person will become more expensive. Social Security, Medicare, and Medicaid—all of which focus their benefits largely on the seniors and disabled—utilize 42 percent of the federal budget even now, before the baby boomers begin to retire (Antos, 2008).

Unprecedented Health Care Spending

With increasing health care costs and our changing demographic, health care spending continues to rise more rapidly than income and other spending. Over the past 40 years, “health care spending has consistently grown roughly one-third faster than the economy” (Antos, 2008). A report released by the Kaiser Family Foundation stated that U.S. health care spending rose from 8.8 percent of the gross domestic product (GDP) in 1980 to 16.0 percent of GDP in 2006.

Additionally, we have a population of people with disabilities who are heavy users of health care dollars. In fiscal year 2005, the United States spent 40.8 percent of total Medicaid expenditures on health care services for persons with disabilities (Kaiser State Health Facts, 2005). Together, seniors and people with disabilities utilized nearly 67 percent of total Medicaid service dollars, but made up less than one-quarter of the Medicaid population. While studies in the past two decades have revealed substantial declines in the rates of disability and functional limitation for older persons, the United States has already seen an increase in the number of young veterans with disabilities returning home from the most recent wars in Iraq and Afghanistan. According to the Veterans Affairs Department, the number of disabled veterans has increased 25 percent since 2001.

HEALTH CARE COSTS CONTINUE UNPRECEDENTED RISE



Source: Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group

Uninsured

The Kaiser Commission on Medicaid and the Uninsured estimated that roughly 45 million Americans were uninsured in 2007. The economic vagaries of the past few years and rising health care costs will likely result in an increase in that number in the coming years. Approximately 23 percent of uninsured adults go without needed health care and many go without preventive health care and wellness screenings. Uninsured adults are less likely to receive follow-up care after a chronic condition is diagnosed, resulting in a greater likelihood of declining health. Inadequate access to preventive health screenings and follow-up care for chronic conditions will yield a

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sicker population of adults and seniors who will require more intensive therapies and treatment to live. Upon turning 65 or becoming disabled, previously uninsured persons may qualify for Medicare and potentially Medicaid, adding to the rolls and costs of government-sponsored health care. Private long term care insurance is beginning to be sold. There are efforts in many states to encourage public private partnership programs that provide incentives to purchase long term care insurance. However, private long term care insurance can be financially unattainable for many people. Therefore, many people have not yet purchased insurance for long term services and supports, which leaves them highly vulnerable for the high costs that can occur when long term care is needed.

Long Term Services and Supports

Long term services and supports consist of a range of services that are designed to meet chronic medical, functional, personal and social needs of people with disabilities and seniors with chronic health conditions. Long term services and supports often involve assistance with activities of daily living and personal care, such as grooming and bathing. In state Medicaid systems, eligibility for long term services is typically determined by an individual's categorical need for nursing home level of care or institutional equivalent. Once a person is enrolled in a Medicaid long term service program, they are eligible to receive assistance and support services in a nursing facility, other institutional setting, or in a home or community-based environment. A person's placement is determined by their acuity and the parameters of the Medicaid program.

In July 2008, the AARP Public Policy Institute released a report stating that, on average, Medicaid expenditures can assist nearly three seniors and/or people with disabilities in home and community-based services (HCBS) for the same cost of providing care to one person in a nursing facility. Additionally, 87 percent of persons age 50 and older with disabilities preferred to live in their own home (Gibson, 2003). The report determined that "to the extent that states provide HCBS instead of nursing home services, the shift in service delivery can be both cost-effective and responsive to the preferences of people with disabilities" (Kassner, 2008).

The evolution of Western medicine gave rise to a medical model that relied on specialized expert physicians to diagnose and prescribe the course of treatment for acute health care conditions, such as heart attacks and infections. Once diagnosed, individuals follow the treatment regimen ordered by the physician without questioning or providing input

TOP 10 MUST READ ARTICLES

1. *Creating Livable Communities*, by the National Council on Disability, October 31, 2006.
2. *The State of 21st Century Financial Incentives for Americans with Disabilities*, by the National Council on Disability, August 11, 2008.
3. *Building on the Ticket: A New Paradigm for Investing in Economic Self-Sufficiency for People with Significant Disabilities*, Ticket to Work Final Report to the President and Congress, December 2007.
4. *A Balancing Act: State Long Term Care Reform*, AARP Public Policy Institute, July 2008.
5. *Toward Independence*, by the National Council on Disability, February 1986.
6. *Advancing Self-Sufficiency for Medicaid Beneficiaries: Meeting the Challenges of the Olmstead Mandate*, Rutgers, March 2008.
7. *America's Regional Demographics in the '00s Decade*, The Brookings Institute, November 2006.
8. *This is the Story of the Most Fearless Entrepreneur Ever: The Human Brain*, John Hockenberry.
9. *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*, Office of the Surgeon General, January 2008.
10. *Frameworks of Integrated Care for the Elderly: A Systematic Review*, CPRN Research Report, April 2008.

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into the directive. This prescriptive model has proven effective for acute care and has contributed to better management of acute symptoms and illnesses. In an effort to emulate the success of the acute care model, health care experts and public health officials replicated the medical model for use in the long term service system.

However, in the long term service system, using a prescriptive medical model that dictates the course of action, such as where a person lives and the personal care they receive, is far more intrusive than prescribing a treatment regimen for a broken arm. The medical model applied to a publicly funded long term service system like Medicaid, essentially directs activities of daily living and personal care and determines a person's living environment without input from the individual. Application of this prescriptive model in a long term service system has several demeaning drawbacks:

- It is difficult to preserve a person's dignity and independence when he or she is forced into a living situation or environment without any input into the decision.
- Individuals receiving assistance with personal care are forced to rely on a stranger or someone else's choosing to perform intimate personal services, such as bathing and grooming. Since many Medicaid programs contract with home health agencies to provide services to people living in their own homes, individuals are forced to receive personal assistance during agency business hours, despite their possible desire to receive such assistance at night or on the weekends.
- When a Medicaid recipient is unsatisfied with his or her service, it is nearly impossible for the individual to move out of a nursing facility or eliminate the bad provider and hire someone else of their choosing.



Mathematica Policy Research, Inc. found that 99 percent of Florida Cash and Counseling participants were satisfied with their caregivers.

Positive transformational change cannot occur without first embracing the philosophy that seniors and people with disabilities have the right to live in an environment of their choice and exercise personal preference for the types of services they receive and by whom those services are provided. Some states have already adopted this philosophy and have piloted and implemented programs that promote independence and personal preference for seniors and persons with disabilities. Despite the **high satisfaction** among the persons

served, these programs are the exception to the rule and still face regulatory constraints in order to expand to serve more individuals and provide services and supports within a person's home or community-based setting. Without careful planning and development of an infrastructure that promotes independence and personal preference for seniors and persons with disabilities, we will continue our reliance on institutional facilities—which have proven to be more costly than home and community-based alternatives and less desirable for persons forced into occupancy in such facilities.

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CALL TO ACTION

We, the National Advisory Board, believe that broad scale, sweeping, significant changes are required to ensure that independence and dignity are preserved for those who require care. Health care dollars must be used wisely to curb the spiraling costs of acute and long term services. The required paradigm shift can only be accomplished with the meaningful involvement in planning of those who are affected and who will be affected by significant change. This includes policymakers, program developers, human service providers, the medical community, and, most of all, consumers (seniors, persons with disabilities, family members of seniors and persons with disabilities, and future seniors or people who will become disabled).

As a Board, our experience has taught us that broad scale change requires broad scale consensus. We as a nation have to agree upon a reasonable outcome and we have to engage in collaborative, community-based planning and education exercises that promote a cultural shift. **This requires a shift in how we Americans take responsibility for our own health.** The changing demographic of our population necessitates that the medical community understands the holistic needs of individuals and chronic needs of an aging population. The spiraling cost of health care commands a philosophical rethinking about publicly funded health care and its need for improved technologies and collaborative infrastructure to meet the needs of all persons across a full spectrum of ages and disabilities.

Transformational shift in our health care and social service delivery system requires significant changes that leverage the benefits of successful models without being held captive to legacy systems or policies that no longer work. The growing demand for people to live outside of costly institutionalized care creates greater need to tap into modern technology and assistive devices that enable people to live in the environment of their choice and self-manage chronic conditions. America's policy leaders must be compelled to move beyond debates on regulations and financing mechanisms because structural change will have real dollar costs. Each of us—consumers, the medical community, policymakers, program directors, academics, health care organizations, and human service providers—have a stake in the health care system and a responsibility to help transform it. This Call To Action challenges each of us to transform our health care system into one that integrates acute and long term services to appropriately meet the needs of seniors, people with disabilities, and future generations.



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1. ENHANCE SELF-CARE THROUGH IMPROVED COORDINATION

According to the Centers for Disease Control (CDC), chronic diseases—such as cardiovascular disease (primarily heart disease and stroke), cancer, and diabetes—are among the most prevalent, costly, and preventable of all health problems. In 2005, 133 million people (almost half of all Americans) lived with at least one chronic condition. The medical costs to care for people with chronic disease exceeded **\$1.5 trillion**. In 2005, chronic diseases accounted for 70 percent of all deaths in the United States.

Research studies suggest that “patients with effective self-management skills make better use of health care professionals’ time and have enhanced self-care” (Barlow, 2000). Other research indicates that many “self-management programs for patients with conditions such as diabetes and hypertension are effective in reducing hospitalizations and hospital lengths of stay” (Lorig, 1999). To the extent that individuals are further supported through the use of medical homes, hospital admissions can be reduced by as much as 20 percent and total medical care costs can be reduced by 7 percent (Paulus, 2008). Supporting a holistic approach to health care that encourages the use of a medical home empowers individuals to become participants in the management of their own health and supports physicians in delivering evidence-based health care.

**1.5 trillion seconds ago (47,319 years)
the earth was in a glacial period
and Neanderthal people roamed
the plains of Europe.**

Applying the Medical Home Concept

The medical home concept is a holistic and personalized approach to health care that goes beyond acute episodes of illness. The concept of the medical home was created in 1967 by the American Academy of Pediatrics (AAP), initially referring to a centralized location for archiving a child’s medical record. The concept has since evolved to a coordinated system which hinges upon a personal relationship between the individual and his or her physician. The physician serves as the primary coordinator of care and bridges the delivery of health care across all elements of the complex medical system. In March 2007, the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association released the *Joint Principles of the Patient-Centered Medical Home*, which include:

- **Personal Relationship:** Each patient has an ongoing relationship with a personal physician² trained to provide first contact, continuous care, and comprehensive care.
- **Team Approach:** The personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing patient care.
- **Comprehensive:** The personal physician is responsible for providing for all the patient’s health care needs at all stages of life or taking responsibility for appropriately arranging care with other qualified professionals.
- **Coordination:** Care is coordinated and integrated across all domains of the health care system, facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they want it.

² The term “personal physician” refers to the primary physician responsible for coordinating care for an individual. The personal physician may be a primary care physician, general practitioner, or specialized practitioner.

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- **Quality and Safety:** Quality and safety are hallmarks of the medical home. This includes using electronic medical records and technology to provide decision support for evidence-based treatments and patient and physician involvement in continuous quality improvement.
- **Expanded Access:** Enhanced access to care is available through systems such as open scheduling, expanded hours, and new options for communication between patients, physicians, and practice staff.
- **Added Value:** This includes payment that appropriately compensates for the added value provided to patients who have a patient-centered medical home.

Paramount to the medical home concept is a centralized repository of information that can be easily accessed by physicians involved in the medical treatment of individuals. The centralized repository of information can be housed and coordinated through an organized care delivery system or through a fee-for-service model. The robust electronic sharing of information among physicians allows for better continuity and coordination of care. An open source technology platform supports health information exchange, quality outcome collection, and incorporation of evidence-based guidelines and decision support tools that aid physicians in determining the best treatment options available to individuals. The open source platform also allows individuals to self-monitor and track their own health care. To date, “there has not been an alignment of services to support the needed services, technology, or processes to ensure that a patient has an accountable health care delivery system” (Dunn, 2008). In order to transform our system of care from a prescriptive form of health care delivery to one that empowers people to take an active role in their own health care, we must:

- Ensure the health system is safe, coordinated, cost-effective, and accountable. Expand the use of care coordination and service navigation which links individuals to additional support services such as housing, transportation, personal assistance, and employment.
- Invest resources in technology that improves individuals’ ability to self-monitor chronic health conditions.
- Educate consumers on the specific tasks and responsibilities for managing their whole health, and motivate consumers to understand, demand, and choose higher quality health care.
- Promote the use of data integration and continuity and coordination of care through the use of health information exchange and electronic health records.
- Support a centralized knowledge base of information that contains the community resources available to assist persons at every stage of life for every type of health care need. Information should be available to consumers, families, providers, and the community at large.
- Encourage a system of quality improvement that uses evidence-based guidelines, information technology, and decision support tools to guide health care options.
- Elevate the use of technology to streamline the delivery of care, coordinate information into one consolidated repository that can facilitate more efficient health care delivery, and increase use of in-home monitoring equipment and personalized health records.

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The following scenario provides an example of the type of health care system that could be achieved through a person-centered medical home approach.

Lynn Whitfield has diabetes and is a semi-retired public relations manager who suffered a heart attack late last year and was diagnosed with congestive heart failure (CHF). Following her surgery and prior to discharge, Lynn participated in a Chronic Disease Self-Management program that was developed through a collaboration of federal and state health programs, community health centers, national coalitions and associations of physicians and providers, and private industry. The disease-specific training programs were organized into four training modules: (1) clinical medicine, which provided information on medications, acute illnesses, emergencies, and the types of questions one should ask their physicians and specialists; (2) wellness, which addressed nutrition, physical activity, and emotional and mental health; (3) independent living, which addressed health and human services available in the community; and (4) technology, which detailed the types of technology available to assist with disease-specific self-management techniques. The module also described the process by which certain technologies (such as sub-dermal body sensors) wirelessly transmit health data to a person's physician so he or she may monitor the individual's care in a remote location.



Each of the disease-specific training programs contained self-management tools and was available in multiple languages and communication formats. Lynn had access to printed materials, videos, and the Chronic Disease Self-Management program Web site. The Web site offered online interactive health and wellness tools such as nutrition guides, activity logs, diet and meal planning, and disease-specific diaries to record blood sugar levels, heart rate, blood pressure, etc. In the event that Lynn requires a refresher course, she has access to in-person training at various community centers, libraries, places of worship, employer sites or schools.

The training that Lynn received to live with CHF and diabetes also educated her about the types of assistive medical devices available to help monitor her health. In addition to her transtelephonic monitoring system which monitors her pacemaker via the phone, Lynn has a sub-dermal transmitter to monitor and transmit her heart rate, blood pressure, and glucose levels to her Personal Health Tracker on an ongoing basis. The Personal Health Tracker enables Lynn to chart, over time, her blood pressure, heart rate, and blood glucose levels. By viewing daily, weekly, and monthly graphs and charts on her computer, Lynn can determine the times of day when her blood glucose levels or blood pressure spike or dip into a dangerous range. Equipped with this information, Lynn can adjust her diet, activity level, and/or medication to ensure her health status and vitals stay within an acceptable range.

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Lynn's sub-dermal transmitter also wirelessly transmits information to her primary care physician (PCP) who serves as the medical home of Lynn's health information. The PCP's staff is alerted of any irregular functioning that requires medical assistance. Lynn and her PCP determined that Lynn would also upload information from her Personal Health Tracker to the PCP's office on a monthly basis. Lynn's personal health information becomes part of her quality health record which is coordinated by her physician. Serving as Lynn's medical home, Lynn's PCP can coordinate additional follow-up or referral to specialists based on the information received from Lynn and her sub-dermal transmitter. In the event that Lynn's health requires input from a specialist, Lynn's PCP can authorize the ancillary provider to have secure access to Lynn's quality health record.

Please note: These are representations and not actual people.

The health care system in general must be transformed from one that focuses on hospitals and episodic illnesses to one that assists individuals in self-managing their whole health, with the support of providers and communities. State-of-the-art technology can further support individuals to monitor their own health and electronically transmit data to physicians. Individuals who have established relationships with their PCPs (who serve as a medical home) are better supported to self-monitor chronic illness and have a single point of contact when a change in health status or emergency occurs. Individuals supported by a care coordinator (who serves as the one-stop service navigator) are able to access social support services with greater efficiency. Individuals, families, providers, care coordinators, and community service organizations that have access to a centralized knowledgebase of community support resources are further educated on the exact types of services and supports available in the community. Communities equipped with this type of centralized repository of information can also better respond to the needs of people in everyday life as well as in emergency situations.

America's medical community must be supported with increased education regarding the chronic health needs of an aging population. Personal physicians must be fundamentally and financially encouraged to serve as the medical home for individuals and coordinate an individual's health care across all elements of the health care system and throughout all stages of life. It is essential that there be an investment in technology to improve this collaboration within the medical community, by encouraging evidence-based practice models for treatment of chronic health issues and co-morbidities. Physicians who have access to decision support tools have increased ability to make informed decisions about quality health care options available to the individual. Through self-care monitoring, preventive health, and physician supported medical options, persons have the ability to live in the environment of their choice and play a key role in the decisions affecting their care.

CALL TO ACTION DIALOGUE:

Transform America's health care system from one that focuses on episodic illnesses to one that assists individuals in self-managing their whole health, with the support of providers and communities.

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2. ENCOURAGE COMMUNITY INTEGRATION AND INVOLVEMENT

Every American has the right to fully participate in the social and economic mainstream and enjoy the benefits and freedom associated with that participation. Although progress has been made, much of the public policy affecting people with disabilities does not yet promote the goals of the 1990 Americans with Disabilities Act—equality of opportunity, full participation, independent living, and economic self-sufficiency. The fact remains that the majority of older adults and people with disabilities receive long term services in institutions instead of home and community-based settings (Kassner, 2008). Other people with physical disabilities or mental illness who do not receive care in an institutionalized setting must constantly battle financial, environmental, and attitudinal barriers that inhibit their full integration into the community. Such was the case with Patricia:

*For more than 25 years, Patricia Kramer battled major depression, PTSD, alcoholism and asthma. When she left her abusive husband, Patricia was unable to hold a job for more than a few weeks. Estranged from her family of origin, Patricia became homeless. Without proper medical care, her asthma intensified and she sought help at a community health clinic. The case worker determined that Patricia qualified for **Supplemental Security Income (SSI)** and Medicaid and was referred to a homeless shelter for women.*

Patricia received treatment for her asthma and was prescribed an anti-depressant for her depression. After several days, Patricia was able to move to a transitional residence for homeless women with substance abuse disorders and began taking part in 12-step groups. She enrolled at the psychosocial clubhouse and began pre-employment training in the clerical unit.

SSI is a federal income supplement program designed to assist elderly, blind, and disabled people who have little or no income.

It seemed that Patricia was on the road to recovery. She excelled in the psychosocial program and was placed in an office firm, where her abilities were recognized and she was quickly assigned more hours and a small increase in pay. The next month, along with her reduced SSI check, Patricia received notice that her Medicaid would be discontinued if she continued earning her present salary. She immediately quit her job and started drinking. Ashamed, she did not return to the psychosocial program, was kicked out of transitional housing and became homeless once more.

Please note: These are representations and not actual people.

In response to public concern, the federal government developed several programs aimed at educating people about the services available to foster community integration. The Aging and Disability Resource Center (ADRC) grant funded by the Administration on Aging (AoA) and the Systems Transformation Grant (STG) supplied by Centers for Medicare and Medicaid Services (CMS) provide funding for states to develop initiatives and support networks that aid in transitioning people out of institutional care and into the community. These funding streams also support initiatives to coordinate a system of alternative services and settings that enable seniors and people with disabilities to live in the community and avoid institutionalization in the future.

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Grants funded by the ADRC and CMS allowed the state of Virginia to develop its *No Wrong Door* program that offers a “virtual single point of entry for accessing public and private health and human services for adults in Virginia.” The Virginia No Wrong Door program is a collaborative among state agencies and private, non-profit partners. The co-location of information for the No Wrong Door program permits users to access information regarding resources, services, and referrals for acute care, long term services, mental health, transportation, and personal care at physical locations, online, or by phone. The centralized repository of information streamlines application and eligibility processes and eliminates cumbersome administrative procedures that often plague government-sponsored health and human service programs. The one-stop approach empowers people like Patricia to seek the medical, social, housing, and employment services they need to integrate themselves into all aspects of society.

In a modernized infrastructure, the case coordinator processed Patricia’s eligibility for multiple programs and services in the state’s online Health and Human Support Resource Center (HHRC). The case coordinator determined that Patricia was eligible for SSI, Medicaid, Ticket to Work, and housing assistance. She received a health and mental health screening and immediate asthma care. At the follow-up appointment Patricia met with the clinic behaviorist who videophoned the psychiatric nurse practitioner at the community mental health center. Using psychiatric telehealth protocols, the clinician examined her, prescribed a short term anti-depressant and referred her to therapist with expertise co-occurring mental illness and addiction. Patricia began attending a PTSD support group.

Patricia met with a self-directed support coordinator (SDSC) who worked with her to develop her own self-directed support plan (SDS-Plan). Through her SDS-Plan, Patricia identified several personal goals to maintain sobriety, recover from depression and PTSD, obtain housing, and work as a bookkeeper. She also expressed the desire to make new friends and re-establish a relationship with her estranged family.

The SDSC paired Patricia with a job coach to get a part-time clerical position at an accounting firm and enroll in an accounting course at the community college. After one month, Patricia chose to move to a HUD-supported apartment complex that was close to work and shopping and had common areas for residents to congregate. In conjunction with others, Patricia organized a resident empowerment network (REN), which serves as a neighborhood social support group for residents within the complex. The REN affords residents the opportunity to get to know others in the community and provide support to one another as needed. For instance, Patricia’s neighbor, Sally Ramirez, is 72 years old and sometimes requires assistance with carrying groceries to her apartment. Since Patricia doesn’t have a vehicle, she rides with Sally to the grocery store to go shopping and Patricia assists Sally with her groceries at home.



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The co-location of information enabled the SDS coordinator to screen Patricia's eligibility for multiple programs based on the goals that Patricia provided in the development of her SDS plan. It is this type of coordination and customization that is lost in a fragmented system. Information-sharing capabilities of a coordinated interconnected infrastructure promote better communication and coordination among entities, provide seamless pathways to services, and enable a seamless transition into the community.

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Although interdisciplinary planning and support coordination are effective at eliminating barriers to accessing needed services, this alone will not make community integration more accessible for people. We—as policymakers, program directors, city planners, health and human services providers, health care organizations, and consumers—must be compelled to:

- Increase opportunities for seniors and people with disabilities to live in the community by ensuring the availability of housing that is affordable, safe, and universal in design to accommodate all persons across a spectrum of ages and disabilities.
- Enhance education, advocacy, and outreach regarding the community living support options that are available to people who seek to transition out of institutional care.
- Augment outreach mechanisms to educate individuals and family members of seniors and people with disabilities who are at risk of transitioning to an institutional setting.
- Promote employment for persons who express the desire to work and participate in the economic mainstream.
- Promote opportunities for enhanced community participation for people currently residing in institutions.
- Recruit and train direct care workers and create a career path for peer support navigators who assist individuals and their families with obtaining services and supports.
- Promote the use of data integration and continuity and coordination of care through the use of health information exchange.
- Devote resources to the development and implementation of innovative technology that enables people to self manage chronic health conditions, interactively communicate with health professionals via online technology, and live independently through the innovative use of assistive technology.

CALL TO ACTION DIALOGUE:

Coordinate support services, housing, and transportation so that people are able to participate in the social, economic, educational, and recreational activities available through community living.

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3. EXPAND ACCESSIBILITY OF SERVICES AND SUPPORTS

As part of their independent health care reform, many states are employing approaches to achieve more balanced long term service and support systems for seniors and persons with disabilities. These states use “pooled financing” or “coordinated funding” as a financing mechanism to consolidate Medicare and Medicaid funding. The coordination of multiple funding sources promotes greater freedom and flexibility for state administration to:

- Integrate acute and long term services
- Promote choice for seniors and persons with disabilities to access services and supports they need to remain at home or live in the community
- Decrease or eliminate service fragmentation
- Achieve greater cost effectiveness by increasing use of home and community-based services and decreasing use of nursing facility services (Hendrickson, 2004).



In states in which these programs exist, many Medicaid/Medicare dually qualifying beneficiaries are able to obtain the services and supports they need to live independently in the environment of their choice. Despite the popularity of these types of integrated programs that promote personal preference for home and community-based services, they are the exception to the rule. According to the 2004 reports from CMS, there are 1.7 million Medicaid participants receiving services in a nursing home and only 1.3 million receiving services through home and community-based services. Yet, in a recent study reported by the AARP, 87 percent of people over age 50 with disabilities preferred to receive assistance with daily activities in their own homes (Gibson, 2003).

Other seniors and people with disabilities who do not qualify for Medicaid but require personal care services like bathing, grooming, or cooking must rely on **support from family** or friends. If family assistance is not an option, they must pay for someone to come to their home to provide assistance. Seniors and people with disabilities who have well-established financial portfolios will not feel the financial pinch as much as other people who have incomes just above the cutoff for Medicaid eligibility. Persons who are financially unable to purchase personal care assistance are forced to spend down savings and assets to financially qualify for Medicaid, or they have to rely on a friend or family member to provide the needed assistance, even at the expense of quitting a job to do so. Families often resort to these options to enable their loved ones to remain at home rather than be placed in a nursing facility.

In 2006, the estimated value of unpaid family care-giving was over \$350 billion.

There is still another subset of the population who requires personal assistance, does not qualify for Medicaid, and does not have friends or family in a position to assist them. Unless these individuals can afford to pay a personal care attendant, they will likely be forced into nursing facilities because Medicare and supplemental policies do not cover the cost of personal assistance services. Without access to appropriate services and supports to live independently, these individuals must take occupancy in a nursing facility and eventually spend down their savings to qualify for Medicaid. Once they qualify, their choices for housing outside of a nursing facility are greatly diminished because they no longer have the assets and accumulated wealth they need to secure housing in their preferred area.

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Without an array of services from which persons can choose to live independently, individuals are expected to go where the system takes them, despite what their personal preference may be. In addition, individuals and their families are, in essence, coerced into a state of poverty so that they may obtain the benefits and supportive services they need to be part of the community. These actions have the potential to create an economic impact far greater than expanding a service array for a government-funded health care program. To help you understand some of the implications of the current system and appreciate the benefits of a changed system, we offer the following scenarios.

Current System: *John Lee, a 69-year-old diabetic, had a stroke which left him unable to walk and with limited use of his right arm. He required the use of a wheelchair and full-time assistance with personal care, meal preparation, and eating. John and his wife, Mary, were faced with the decision of placing John in a nursing facility or caring for him at home with full-time assistance. Since Medicare and John's supplemental insurance did not cover the cost of a personal care attendant, Mary, who is 57 years old, quit her teaching job to care for him. They spent much of their savings on John's medications and various medical and support expenses. Mary, unable to garner an income, no longer paid into Social Security, Medicare, and other taxes, and eventually qualified for Medicaid after she depleted their savings to care for John. Prior to John's death, Mary injured herself by lifting him. Mary's injury required a surgery, three-day hospitalization, and rehabilitation—costing the state's Medicaid program \$65,000. Had John's Medicare benefits paid for attendant care that John required, Mary would not have quit her job, depleted her savings, qualified for Medicaid, and would not have cost the Medicaid program \$65,000 for an injury that could have been avoided.*

Modernized Infrastructure: *John is enrolled in a creative program collaboratively managed at the state and federal level to enable John and Mary to hire and train a personal care attendant. The personal care attendant assists John with activities of daily living, meal preparation, and eating while Mary continues to work as a teacher. John's personal care attendant enables him to resume his daily activities and live at home with Mary. Since John receives assistance during the day, Mary continues to work and pay nearly \$15,000 per year in state and federal taxes and receives health insurance through her employer.*

Please note: These are representations and not actual people.



The total estimated cost of diabetes in 2007 was \$174 billion (\$116 billion in excess medical expenditures and \$58 billion in reduced national productivity).

The scenario of John and Mary in the current system exemplifies the negative economic repercussions of having limited service offerings and neglecting to treat the holistic needs of a person. Many seniors and people with disabilities have co-morbid conditions where chronic health conditions are compounded with physical disabilities, and/or depression, anxiety, or substance abuse. When the holistic needs of the person are not

met, one condition compounds another which can have disastrous and costly effects. For example, if a person over age 65 has diabetes and requires assistance with meal preparation and proper diet control—a benefit not paid for by Medicare—he may eat poorly and continue

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unhealthy eating habits. Poor diet control will exacerbate his diabetes and potentially require him to be hospitalized. In the case of John and Mary, John was able to avoid being placed in a nursing facility, but only at the cost of Mary quitting her job to care for John, and subsequently injuring herself while doing so. Had Mary injured John at any time while she was lifting him, John would have been hospitalized at a cost much greater due to his compounded health conditions.

CALL TO ACTION DIALOGUE:

Retool programs and regulations to enable people to access the services they need to live independently without creating financial hardship for the family.

Moving forward, it is necessary to envision a future in which persons may access the services they need to live independently, while avoiding hardship to the family. Furthermore, it is necessary to move beyond a health system that only provides treatment interventions for episodic illnesses. Instead, the United States must modernize its infrastructure to meet the holistic needs of individuals and make services and supports easily accessible for persons in need.

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4. UPHOLD PERSONAL PREFERENCE

Upholding personal preference is paramount when designing long term services and supports for seniors and persons with disabilities. Long term service systems must be responsive to the needs of persons across a full spectrum of disabilities and ages. Likewise, these systems must enable people to exercise choice about where they would like to live and control over the services they receive. Historically, the majority of long term services funding has paid for the provision of services in institutional settings. While many states have developed home and community-based programs that enable people to receive long term services in their homes or other residential settings, the majority of funding for long term services continues to be spent on institutional care (Kassner, 2008). This imbalance is due, in part, to the existence of policies, regulations, and programs that present barriers to the provision of home and community services and personal control over services provided (CMS, 2003).

In response to public concern, CMS recognized the need to develop a mechanism to enable states to enact legislation, overcome barriers, and create enduring improvements in community-integrated services and long term support systems. Various CMS grants and demonstration projects have allowed states to explore and implement systems transformation initiatives that enable individuals of all ages to live in the environment of their choice and exercise more control over the services they receive. Embodied in the principles of self-determination³, these programs enable people to choose from an array of services, self-direct and purchase the assistance they receive, express their choice about who provides care, and participate fully in competitive employment and community involvement. Two separate initiatives, Money Follows the Person and **Cash and Counseling**, have each yielded positive outcomes for people with disabilities and seniors who wish to live independently in the community and apply personal preference over the services and supports they receive. The following scenario provides an example of what can occur given our current infrastructure.

Cash and Counseling was originally created as a demonstration project in the 1990s through a partnership between the Department of Health and Human Services and the Robert Wood Johnson Foundation.

³ The Self-Determination for People with Developmental Disabilities Program was a national program that began in 1996 to help 18 states implement a more cost-effective system for serving persons with developmental disabilities while simultaneously giving those persons and their families more choice in determining the services they receive. The core principles of self-determination include: freedom, authority, support, responsibility, and confirmation.

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Leticia Reyes is 27 years old and was recently placed in an intermediate care facility for the mentally retarded (ICF/MR) after the sudden death of her mother. Leticia has autism and participated in a supported employment program through her high school that assisted her to get a job at a local florist. In addition to working part time, Leticia participated in music classes at her neighborhood cultural center playing traditional Spanish music at various festivals. The ICF/MR facility where she was placed was located 10 miles away from her job, the community where she grew up, and all of her friends. Since the facility did not provide transportation to and from work, Leticia was forced to quit her job at the florist and could no longer participate in the music classes at her cultural center. During Leticia's stay at the ICF/MR facility, she experienced stress and anxiety because she couldn't participate in her music classes. She expressed to her care manager that she wanted to leave the facility and live closer to the florist so that she could continue to work, play music, and see her friends.



The state where Leticia lives received a CMS grant for the Money Follows the Person (MFP) initiative. With the help of a care manager at the ICF/MR facility, Leticia applied to transition out of the facility and move to an independent living home in her old neighborhood. While the MFP initiative would allow Leticia to transfer out of the ICF/MR facility, the state's Medicaid state plan did not cover personal assistance services in an independent living home. With the right supports and services, Leticia could live in her own apartment. However, Leticia has not been able to accumulate savings and did not have an income that would make housing affordable.

To seamlessly meet the needs of persons that Medicaid programs are intended to serve, the best practices of proven and successful programs must be integrated with one another. Programs complement one another when they share the philosophy that **people**

Researchers found that allowing a person to manage their own personal assistance budget can eliminate fraud and inappropriate service expenditures.

across the spectrum of ages and disabilities have the right to choose the services they receive and by whom and in the environment of their choice.

These complementary programs could blend funding and services to support seamless transitions throughout the health and social service system as a person experiences a change in needs. For example, MFP is a "system of flexible financing for long term services and supports

that enables available funds to move with the individual to the most appropriate and preferred setting as the individual's needs and preferences change (CMS, 2006)." The MFP approach allows Medicaid funds budgeted for institutional services to be spent on home and community services when individuals move from nursing facilities into the community. The Cash and Counseling (sometimes called Self-Direction) approach creates **individual budgets** whereby individuals have the ability to purchase and manage personal assistance and other long term services and supports. Self-direction encompasses the principles of self-determination by empowering people to hire and pay friends or family members as caregivers, further enhancing choice about the types of services the person receives and from whom. Both of these programs provide beneficial services and resources for individuals during critical transitions to live independently.

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Implementation of MFP and Self-Direction initiatives has been effective for more persons to transition from institutional settings to community settings and self-direct support services necessary to sustain their independence. These two programs are separate and are not necessarily implemented together. The initiatives share a common focus of reducing the number of people institutionalized by establishing an infrastructure whereby individuals exercise choice about where they live and the types of services they receive and from whom. Implementing the programs to complement one another and transition more people into the environment of their choice and personally direct services is in the best interest of the individual and also has potential for the greatest overall value in the future. We envision a future in which Leticia is able to live in the environment of her choice and self-direct the services she needs to live independently. The following represents a futuristic scenario of Leticia's life in a modernized infrastructure.

After the death of Leticia's mother, one of the state's Self-Directed Support Coordinators (SDSC), Norma Davidson, contacted Leticia to assist her in her recent life transition of living without her mom. Soon it was determined that Leticia required housing. Leticia chose to live in an independent living home in the community where she was raised. With Norma's assistance, Leticia developed a Self-Directed Life Plan that listed all of Leticia's personal goals, objectives, and preferences for the services she required to live in the community. Once Leticia transitioned to her new home, she began to self-direct the personal care services she needed and paid a friend at the cultural center to assist her with laundry, shopping, organizing her daily activities, etc. Since playing music serves as a therapeutic outlet for Leticia, she self-directed a portion of her budget to purchase a new guitar case that enabled her to carry her guitar with less effort to more places. Leticia continues to work part time at the florist, play traditional Spanish music at local festivals and churches around her community, and socialize with her friends in the community where she has lived all of her life.

Please note: These are representations and not actual people.

CALL TO ACTION DIALOGUE:

Leverage the success of long term service models that promote personal strengths and preferences and preserve the dignity of participants. Eliminate legacy systems and policies that no longer work.

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5. EMPOWER PEOPLE TO PARTICIPATE IN THE ECONOMIC MAINSTREAM

According to the National Council on Disability report, *The State of 21st Century Financial Incentives for Americans with Disabilities*, “a child with significant disabilities born in the United State in 2007 has little chance of escaping poverty, despite advances in health care and technology.” This conclusion is due in part to the all-or-nothing dichotomy of (1) public policy that defines disability as the inability to work and obtain **substantial gainful income**, and (2) public assistance that is only provided to one who remains poor and completely dependent on government aid. If provided with the right supports, an individual with disabilities could earn enough income to live without the cash benefit of Social Security Disability Income (SSDI). However, it is the loss of health and personal assistance benefits (Medicaid) that complicates the issue and creates a real disincentive to work and obtain income above the dollar threshold for disability assistance.

A person receiving SSDI cannot earn more than \$940 per month in substantial gainful income.

To be eligible for the SSDI program, the following Social Security definition of disability must be met:

An individual must be unable to engage in any Substantial Gainful Activity (SGA) due to any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. In addition to being unable to perform his or her previous work, the person cannot, considering age, education, and work experience, engage in any other kind of SGA that exists in the national economy (1967 Amendments).

This definition not only discourages people with disabilities to enter the workforce, it continues to send a message that people with disabilities are inherently unable to support themselves (Ticket to Work, 2008). Furthermore, federal disability assistance eligibility requirements disallow the accumulation of wealth. This prohibits individuals from saving for the future, for retirement, for a down payment on a house, or for obtaining personal assistance an individual may require pending the loss of government-subsidized benefits.

Government programs such as Ticket to Work and Medicaid Buy-In were designed to “remove many of the barriers that previously influenced people’s decisions about going to work because of the concerns over losing health care coverage” (Ticket to Work, 2008).

TOP THREE NOTEWORTHY PROGRAM MODELS WHOSE FULL IMPLEMENTATION AND/OR POTENTIAL IS INHIBITED BY BARRIERS

1. Ticket to Work
2. Medicaid Buy-In
3. Integrated Long Term Care

Yet the full promise of these programs has yet to be realized. According to the Ticket to Work, Final Report to the President and Congress, the biggest barrier to employment reported by beneficiaries is the Social Security definition of disability—that a person cannot engage in any other kind of SGA that exists in the national economy. Modernizing the Social Security definition of disability would provide the opportunity to break down a significant barrier that currently inhibits the employment of millions of Americans who have a disability. Investing resources to educate, train, and support employment of people with disabilities will ensure we no longer elude an entire population of people who can further contribute to our nation’s social and economic welfare. Furthermore, by expanding our labor pool, we would have significantly more eligible candidates who could fill job vacancies created by retiring baby boomers.

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The New Jersey Council on Developmental Disabilities found that another factor that impedes employment for persons with disabilities is the lack of both hard and soft job skills that would otherwise allow them to enter and succeed in the workplace (Heldrich, 2004). Many job seekers with disabilities lack the necessary prior employment experience, higher education, and training that would enable them to advance in a professional career. While the use of job coaching matches workers with disabilities to employment, increased access to higher education and job training would further enhance options for people with disabilities to compete for higher skilled jobs. A modernized infrastructure could eliminate the social, educational, health, transportation, and other barriers to employ more people with disabilities, empower their participation in the economic mainstream, and empower them to contribute to the social and economic health of our nation.

At 27 years old, Dale Harris suffered a spinal cord injury while fighting in Iraq. His injury caused paralysis from the waist down. Upon returning home to his wife and two-year-old child, Dale required home and vehicle modifications to make his environment more accessible. He also required intensive outpatient counseling and pharmacological regimen to assist with his post traumatic stress disorder (PTSD). Dale's wife, Julie, went to work fulltime to help the family meet its financial obligations. Dale participated in an innovative government-funded program that pulls resources from various programs, such as Ticket to Work, Medicaid, and Veterans Affairs, to create an individualized budget from which he could self-direct the purchase of various services and supports he needed to recover from PTSD, continue home modifications, and become economically self-sufficient. Through the Self-Directed Support Plan (SDS-Plan) program, Dale allocated his budget toward home modifications, online classes to obtain his degree, and PTSD recovery programs. Upon receiving his degree in computer assisted drawing (CAD), he obtained employment with a company that specializes in universal workplace design, development, and reengineering. Dale's employer works collaboratively with a supportive employment agency that receives state and federal grants to retrofit universal design in existing workplaces that seek to hire persons requiring workplace adaptations. As a universal design CAD-technician, Dale assists employers to design and reconfigure their workplaces to facilitate accessibility by all individuals, regardless of age or disability.

To ensure that he did not lose his health and long term service and support benefits upon garnering his first paycheck, Dale's employer created a program that provides cash benefit to employees in lieu of participating in the employer's health insurance program. Dale utilized this benefit to participate in a reconfigured Medicaid Buy-In program that provides a gradual step-down or partial disability allowance as his income steadily increases. This program enables people with disabilities to enter the workforce and obtain gainful employment without losing health and long term service and support benefits. As Dale continues to work, the Medicaid Buy-In program will enable him to purchase the services he requires to manage his PTSD, continue his home and vehicle modifications, and maintain successful employment.

Please note: These are representations and not actual people.



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The overarching dichotomy of federal and state program eligibility requirements requires a reevaluation of federal policy which, as currently written, creates a disincentive for people with disabilities to work. A transformational shift that empowers people with disabilities to obtain gainful employment cannot occur without first overturning misconceptions and redefining government terms that convey the idea that people with disabilities are inherently unable to support themselves. This requires a shift in our perception of government-subsidized programs from a social service model to a model that promotes participation in the economic mainstream through the use of tailored supportive employment programs. We must promote the development of employer education



programs about the services provided by workforce development agencies and other entities to support workers with disabilities.

CALL TO ACTION DIALOGUE:

Encourage the employment of people with disabilities by removing disincentives for people to work and redefine antiquated descriptions of disability.

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6. INVEST IN IMPROVED TECHNOLOGY

The application of modern technology in acute and long term services is boundless and rapidly changing. From an individual perspective, technology can assist people with chronic health conditions self-monitor their health status and better manage illnesses. From a health care delivery system perspective, technology facilitates the collection of data for use in program planning, data sharing, oversight, and quality improvement and is the cornerstone of a medical home. Technology is used to improve communication and information sharing among the medical community and can increase continuity of care through improved care coordination. Technological advances will also enhance transportation and enable greater mobility for seniors and people with disabilities and reduce the need to physically transport a person to a physician's office for follow-up visits.

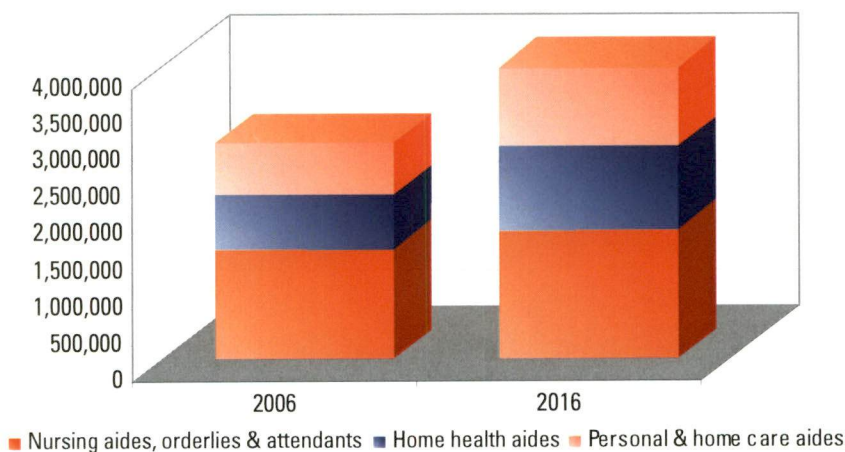
The previous scenarios described the use of personal care services provided by family members, friends, or other entities so that both Leticia and John could avoid being placed in a nursing facility. According to the U.S. Department of Labor, the demand for direct-care workers will increase by 50.6 percent for personal and home care aides, and 48.7 percent for home health aides by 2016. The latest employment estimate for the direct-care workforce will call for an additional 1 million new positions to top 4 million total positions for paid direct-care personnel (U.S. Department of Labor). Still, many seniors and people with disabilities rely on family and friends to

provide needed personal assistance and supports so the individual may remain at home. In 2006, the economic value of unpaid family caregiving was estimated at \$350 billion annually (Kassner, 2008). The workforce shortages the nation faces for direct caregivers should compel our nation to further enhance assistive technologies that would enable people to live in the community and reduce the amount of human service hours required for personal assistance services.

Already, technology exists that allows individuals to communicate more effectively through the use of augmented devices that switch effortlessly from laptop computer to touch screen device. With built-in wireless

connectivity and speech capabilities, individuals have a range of communication options available. Other devices used in self-health monitoring enable persons to transmit health information via the telephone or Internet. For example, a person equipped with a pacemaker can transmit information about the device and their health status to a physician via a transtelephonic monitoring system, thereby eliminating a physical visit to the physician's office.

PROJECTED GROWTH IN DIRECT-CARE WORKFORCE



Source: Paraprofessional Healthcare Institute, April 2008

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Technology companies are on the cusp of producing personalized robotechnology where robots and in-home sensors will wirelessly transmit data to physicians, family, care managers, or emergency departments in the event of a fall, missed medication, or if the person becomes unresponsive to cues from the robot or sensor. Within the next few years, people will have the option to utilize sub-dermal body sensors which will continually monitor heart rate, blood glucose levels, temperature, or blood pressure. These sensors are designed to wirelessly transmit data to authorized medical personnel who may observe an individual's health status and may intervene when an anomaly triggers an alert that a problem exists. Each of these devices will enable people to remain in the community, provide advanced monitoring of chronic health conditions, and reduce the amount of human service hours required for personal assistance. For a health system like Medicaid, these technological advances can result in long term cost savings.

Payton Johnson is 39 years old, was born with spina bifida, and uses a wheelchair to mobilize. Growing up with computers and technology, Payton realized very soon that he could live anywhere and do anything he wanted to do with improved technological assistive devices.

Upon graduating with dual degrees in business management and engineering, Payton aimed his attention at the world of technology to improve assistive devices for persons with disabilities. Payton established a partnership between a wheelchair manufacturer and a vehicle manufacturing company to co-design a hydrogen fuel cell vehicle equipped with an independent mobility device (IMD) that

dually serves as the driver's seat as well as an electric wheelchair. Once in motion, the vehicle automatically charges the lithium-ion battery imbedded in the wheels of the IMD, which can also be charged with alternative power, solar power, or through a regular electric charger.



As the driver's seat, the IMD can wirelessly transmit data—such as scheduled daily activities and contact lists—from the user's PDA cell phone to the vehicle's data system. Both the IMD and the vehicle facilitate voice-activated calling in addition to transcribing voice command to e-mail. The IMD seat fabric is equipped with smart skin technology that monitors body temperature, provides heat or cool relief, detects body hot spots, and memorizes seat positioning. The IMD alerts the user to change positions when it detects heightened pressure on the body and the potential for pain or a decubitus. The IMD is also equipped with peripheral devices such as blood pressure and heart rate monitors that transmit the health data to an on-board data system that can wirelessly transmit the data to the user's personal health record or physician's office.

Since the IMD is able to store information from the user's PDA such as a daily calendar, the voice command capability can remind the user of upcoming appointments or notify the user to take medications at specific times. The IMD's databank can also memorize the footprint of a house or structure and respond to voice activated commands to maneuver throughout the home or a structure such as a grocery store or shopping center. The IMD can also alert emergency services in the event of an emergency situation.

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The preceding scenario demonstrates technology as the skillful conduit between man and machine that facilitates control over one's own life. The possibilities for living independently, self-managing chronic health conditions, or preventing pressure wounds (which have the potential for costly hospitalizations) are infinite through the use of innovative technology. Despite the benefits derived from technological advances, the budget restrictions of government systems restrain the investment of resources in new technology. To further advance technology for health care, resources need to be devoted for continued research and design as well as for looking beyond the next fiscal year to determine the future cost savings of implementing improved technologies.

CALL TO ACTION DIALOGUE:

Invest resources in the continued development of technology that improves individuals' ability to live independently.

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CONCLUSION

The spiraling costs of health care, extraordinary number of uninsured, and historic increase in the number of persons reaching retired status once caught the attention of our entire nation to seek a solution to America's health care crisis. The recent economic vagaries have pulled much of the focus away from health care in an effort to secure the financial soundness of America's economy. However, the crumbling foundation of America's health care system will only be further compromised if we as a nation do not appropriately modernize the health care infrastructure to address the holistic needs of the people with disabilities and seniors. Without building capacity in the current system, Americans will face infinitely more challenges in addressing the needs of our nation's aging demographic and of future generations.

The six foundational principles presented in this paper are, in this National Advisory Board's opinion, the underpinnings of a modernized health care infrastructure. The need for long term services supports will become personal for the majority of Americans at some point in their lives. Therefore, we believe that it is time for all Americans to become involved in transforming our nation's health care infrastructure to a system that:

- Enhances self-care through improved coordination
- Encourages community integration and involvement
- Expands accessibility of services and supports
- Upholds personal preference
- Empowers people to participate in the economic mainstream
- Invests in improved technology.

The personal stories presented in this paper are only a few examples of the challenges Americans face when accessing long term services and supports. We understand that these examples are a small representation of many people and the pervasive challenges that result from our nation's fragmented health care system. Therefore, we, the National Advisory Board, invite you to go to www.declarationforindependence.org or www.mydfi.org and provide your own personal stories and comments regarding this paper. There, you will also find information that will serve to educate you further about these issues. In addition, and most importantly, we invite you to join us in this Call to Action to transform our health care system into one that integrates acute and long term services. It is through this modernized infrastructure that we will appropriately meet the needs of seniors, people with disabilities, and future generations.

www.declarationforindependence.org
www.mydfi.org

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