

The Chronic Care Challenge: Preparing for the 21st Century
The NCCC Vision for Transforming Healthcare
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Introduction

The healthcare industry in the United States is in the midst of profound change. Virtually every dimension of healthcare's approach to administration, financing, and delivery is being questioned. Healthcare reform is at the forefront of critical issues on our national agenda.

Most reform today is driven by two sources: government and employers. Government, plagued by escalating costs to Medicare and Medicaid, has sought to finance care through pre-paid, per capita, fixed-rate financing structures that empower health plans to offer a pre-defined set of benefits to program beneficiaries living within defined service areas. Employers have pursued a similar strategy in seeking to reduce the cost of production and maintain or gain a price advantage over their competitors. Both have employed managed care financing methods to control costs, including HMOs who act on their behalf in contracting with providers and controlling service utilization.

In most cases, providers have responded by pooling their assets with like minded organizations and establishing new administrative and marketing structures that enable them to successfully compete for limited contracting opportunities. These consolidation strategies have been driven primarily by large hospital systems, seeking to maintain or expand their market share and to stabilize their referral base with physicians. Increasingly, consolidation efforts are moving across state lines. More recently, leaders within the nursing home industry have created long-term care alliances to leverage contracting opportunities with HMOs, prepare for new pressures to contain cost, and develop new business opportunities. Consolidation has been pervasive within the home health industry as well. In most cases, however, these efforts have not fundamentally changed the nature of how care is provided.

Last year as part of the Balanced Budget Act of 1997, Congress passed legislation that will expedite the consolidation effort, but still may not fundamentally change how care is provided. Integrated service systems will be able to "go at risk" for Medicare financing without HMOs functioning as third-party payers, and HCFA will soon move Medicare financing of home healthcare and nursing homes to prospective payment. States are also becoming more and more aggressive in moving Medicaid to capitated financing.

Almost all of these changes are focused on reducing the costs of care as provided by hospitals, physicians, home health agencies, and physicians. Providers serving the chronically ill and disabled will still function as separate and unrelated providers, although they may offer different aspects of care to the same person. And, while there is increased recognition of and support for continuity of care for the chronically ill, most cost reduction and consolidation efforts will maintain if not further reinforce unit hospital and long-term care structures, without regard for the cumulative cost and care effects of addressing problems that cross primary, acute, and long-term care service sectors. The focus of reform is still more on the problems of payers and providers than on the problems of people served. It is still more on achieving efficiencies in the operation of existing programs than on containing costs through better care methods, regardless of who provides it.

The National Chronic Care Consortium advocates for a next-stage reform strategy that is rooted in principles of care critical to serving people who have chronic diseases and disabilities. People with

chronic diseases and disabilities are the fastest-growing, highest-cost, most complex user segment in healthcare. Almost 100 million Americans have one or more chronic conditions. Chronic conditions account for about 80 percent of all deaths and 90 percent of all morbidity. Seventy percent of all medical costs relate to people with chronic conditions. One half trillion dollars a year is spent on problems of chronic illness. If we are going to adequately address the cost Containment problems of the future, if we are going to maintain quality care over the long term, it is absolutely vital that we give more attention to the problems of chronic disease and disability.

Since 1990, the NCCC, comprised of 34 of the nation's leading health systems, has focused on establishing chronic care networks (CCNs), or person-centered, community-based, systems-oriented methods for people afflicted with problems of chronic disease and disability. The focus has been on changing the infrastructure of health systems operation to prevent, delay, or minimize the progression of disability associated with chronic conditions. New methods of operation are being established to manage care across time, place, and profession and to provide whatever combination of care is most efficient and effective in achieving cumulative cost and quality objectives.

NCCC members believe that the success of cost containment and the health and well being of Americans requires that we move beyond containing costs and consolidating authority within the confines of existing institutions and establish new methods that are more in keeping with the fundamental nature of problems that are most prevalent today and that will dominate health care well into the 21st century. It requires that we come to grips with the fact that healthcare is changing from an acute to a chronic care business, and that a fragmented, crisis-oriented delivery structure can have adverse effects on the quality of life for people with chronic conditions. It requires that we view what we do through the lenses of people who will be the primary users of healthcare for the next 30 years and transform operations to be more in keeping with the prevailing characteristics of chronic disease and disability.

It is increasingly important that we think about healthcare reform in waves, with an eye toward current and next stage marketplace conditions and that we recognize change as constant rather than transitional.

We can think about the current wave of reform driven primarily by managed care financing and marketplace competition. The tenets of managed "care" are yet to be fully realized. The primary purpose of those who purchase care has been to reduce the flow of money to providers of care in order to achieve greater efficiencies in care delivery. To date, these pressures have been sufficiently strong that most providers have been forced to downsize without fundamentally changing the mix of program operations. Hospitals, physicians, nursing homes, home health agencies, and other care providers continue to function as unrelated businesses. Providers have responded to a change in payment methods, but not to a change in the nature of presenting problems.

While in the midst of the current healthcare reform wave, we need to begin thinking about the second wave, one that will be far more important to meeting the healthcare needs of the 21st century. Over the next five years we are likely to experience pressures to contain the costs associated with problems of chronic disease and disability. We are likely to experience pressure to move reform from the executive and accounting offices and board rooms to the infrastructures for managing money, information, and care. We are likely to be asked to fundamentally transform our responses to the problems of chronic disease and disability among people living within defined communities, with a focus on cost containment through methods that reduce cost and improve care. Providers are likely to feel pressure to redirect their attention to improving care outcomes for those served and to maintaining customer satisfaction without increasing costs. As a result, a whole new wave of reform is likely to emerge with the focus on the highest cost and fastest growing user group in healthcare, namely people with serious and disabling chronic conditions.

In addition, long-term care, public health, home care, and alternative therapies are likely to become more mainstream. The foundation of care is likely to move from hospitals and nursing homes to the home and to community care centers which empower people to define and manage their own care through the use of new self-care technologies, reinforced by institutions that blend the expertise of public health, primary, acute, and long-term care. Cost containment is likely to become more focused on the accumulation of costs across settings and over the long term, with interventions targeted more toward issues of prevention and with dollars flowing to whatever combination of care is most cost effective in achieving predefined outcomes.

As we prepare for this second wave of reform, we need to do more than consolidate assets. We must not become complacent with the structures of managed care financing. We must find ways to do more with less. Our goal must be to fundamentally change the nature of how we do business, with sensitivity to improving how we care for our most vulnerable citizens.

We must build upon the progress that currently exists without becoming trapped by the needs of new and more powerful mega-institutions with old-line service structures at their core. We must move out of our boxes of component-based management, specialized medicine, and facility-based planning and into more of a collaborative model of care where seemingly disparate programs function as a single system. We must seize the moment and establish a new methods of operation that are more in keeping with what we know will be the primary healthcare business of the 21st century -- problems of chronic disease and disability. We must see through new lenses, learn a new language, develop new skills, and transform the nature of our business to build and preserve healthy communities through more person-centered, systemic approaches to care.

The Nature of Chronic Diseases and Disabilities

The starting point for system transformation is understanding that the needs of people with chronic conditions are fundamentally different from those of other individuals. Chronic diseases are multidimensional, interdependent, disabling, interpersonal, and ongoing. Unfortunately, our current healthcare environment defies the logic of these characteristics. We are not multidimensional; we are highly specialized. We are not interdependent; we are highly fragmented. We focus more on disease than we do on disability. We frequently ignore the benefits of interpersonal relations. And we respond to the crisis of the moment, not to the ongoing nature of chronic conditions.

If we are going to fundamentally transform healthcare to improve quality of life and at the same time to save costs over the long term for those who are being served, we must take into account these characteristics of chronic illness. Chronic care is a systems problem and requires a systems solution.

Multidimensional

In considering healthcare, we make an arbitrary distinction between acute care and long-term care. People think about acute care in terms of hospitals and primary care physicians and about long-term care in terms of nursing homes and home care organizations. People who have chronic diseases and disabilities require the full array of services as their conditions evolve and their needs change. The body, mind, and soul are all affected by and affect problems of chronic disease. Where and how people live are part of the problem and solution. We need to think about and prepare for the multidimensional nature of chronic conditions and not think the problems of chronic illness can be solved with a single pill or any single care intervention.

Interdependent

In healthcare today we tend to organize, finance, and deliver care around three factors: healthcare setting, profession, or funding source. Each place, profession, or funding source has its own system for managing quality and cost. Each uses its own approach to defining the problem, providing care, planning and managing care, and monitoring and reporting costs and results. Each assumes responsibility for chronically impaired people, many times for the same person, yet each functions as if all were unrelated healthcare domains. The fact is, people with chronic diseases and disabilities require the full array of settings, working together to achieve a common care outcome. People with chronic conditions need the full array of healthcare professionals to see themselves are part of the same care team.

Consider a person with a hip fracture-something that is clearly part of the acute care environment but is also a chronic condition that evolves over time. After a person fractures her hip, she probably arrives in an emergency room where she is assessed and is moved into a hospital setting. In the hospital setting, professionals develop and implement a care plan and, increasingly, shorten the length of stay. They move this person to another environment, such as a subacute care facility, where other professionals create and implement another assessment and another set of interventions, and where, increasingly, they shorten the length of stay. The person is discharged from that setting to a nursing home setting, where there is another array of providers who do an assessment and a care plan and who, increasingly, shorten the length of stay to discharge the patient to a home care setting. In home care, there is another assessment, another care plan, and another healthcare professional. In many cases these settings are different organizations, paid by different payer systems that involve different governance structures and different providers. Yet this is the same person with the same problem, simply at a different stage of the condition.

It makes no sense to organize healthcare around these silos of provider operation and not look at the management of care in relation to the evolution of the condition. We are not going to contain cumulative costs and improve overall quality until everyone involved in the care of people with chronic conditions, regardless of training or place of employment, sees themselves as a part of the same team and works together to manage care through a natural care episode.

Disabling

As healthcare professionals, we are trained to respond to healthcare problems in relation to a specific event. Society's cure-oriented, crisis approach to care planning and treatment has resulted in remarkable improvements in acute care and our overall quality of life. However, it has also caused us to wait for problems to occur before we intervene. Preventing, delaying, or minimizing the progression of disability is a critical function of cost and quality - and must be maintained as a compatible concept. It is critical to achieving long-term cost savings through quality care interventions.

In their article, "Preventing Frail Health", Buchner and Wagner (1992) identify the normal aging process as a general decline of functional ability, with certain events pointing a person on a path toward significant, long-term functional dependence. Disability prevention interventions involve preventing the onset of disabling events, retarding the progression toward further dependence once an acute event has occurred, and precluding recurrence and/or optimizing functional recovery. Healthcare interventions at key points in time can minimize high-risk/high-cost events, even though they may be unable to prevent the natural, ongoing decline of functioning which is the result of normal aging. When we think of proactive disability intervention rather than reactive medicine, we are preventing, delaying, or minimizing the progression of disability over an extended period of time.

Personal/Interpersonal

We think about individuals and families in terms of patients who are recipients of our care, rather than as active participants, if not primary managers, in the ongoing care process. When we think about self-help strategies, we think about individuals doing for themselves what healthcare professionals might normally do rather than of empowering individuals to maintain an ongoing, quality, healthy lifestyle, regardless of their stage of disability. As we move into the coming phases of healthcare reform, it is vital that we take into account the fact that chronic diseases and disabilities involve, affect, and are affected by the values and priorities each of us holds, and the relationships we have with spouses, family members, friends, and neighbors. These factors affect the outcomes as well as the problems that a person has at any given time. We need to integrate care with the values, norms, and conditions of those we serve, as well as their family and community of residence.

Ongoing

The last characteristic-and maybe the most significant-of chronic disease and disability is the ongoing nature of chronic illness. It is important that we organize financing, administration, and service delivery around the assumptions that these problems are ongoing, not isolated events. The focus is on what transpires over a *period of time* rather than on what happens at *any point in time*. This defocusing on how we view the problem has significant implications for how we manage our time and resources.

As we consider transforming healthcare, we need-at all levels of public policy, administration, financing, and delivery-to understand that the majority of our problems today are not about evil motives or incompetence. The healthcare industry is filled with honorable, bright people, people who want to do what is right. The problem of our current healthcare environment relates more to governance, programs, financing, and information systems that do not respond to the critical dimensions of chronic care. They do not enable us manage care in relation to the trajectory of chronic disease, to reduce the accumulation of cost over time, and to optimize the health and well being of individuals throughout the evolution of any disease or disability.

Unless we address the ongoing nature of chronic conditions and integrate care over time, we are not going to solve our healthcare problems.

A Trinocular View

Once we understand the nature of chronic diseases and disabilities, the first action we must take is to change the lenses we use for viewing our healthcare environment. The mental lenses that we look through guide our decisions; how we define the problem has as much to do with our training, our perspective on life, and our values, as it does with the nature of the presenting problem.

Within the provider community, there are three main professional groups that will shape how chronic care is practiced: these are people trained in acute care, managed care, and long-term care. While each of these groups is responsible for shaping the delivery of care for chronically impaired people as we enter the 21st century, each sees care through different lenses.

Acute care professionals tend to view chronic care problems in terms of illness and solutions in terms of cure. They are very high-tech in service orientation and organize care in very short-term, episodic approaches. Providers deliver care primarily through highly trained professionals with specialized, one-dimensional views, generally without regard for how one problem is linked with another.

Long-term care professionals, on the other hand, tend to view chronic care problems in terms of function and solutions in terms of care. They are very high-touch in service orientation and organize care over an extended period of time. They assume the problem is ongoing and multidimensional with most of the care requirements coming from paraprofessionals and family.

Managed care professionals, the newest professional group in the United States, tend to view chronic care problems in terms of optimizing health solutions into levels of primary, secondary, and tertiary prevention. They are highly aware in service orientation and emphasize a continuous process of educating people about how life events, such as smoking, diet, exercise and stress, affect health and well-being over the long term.

While we have people involved in healthcare in all of these arenas, the fact is all of these people are serving the same person. And when you look at a person with a chronic disease and think "illness" you are going to respond one way, while if you look at the same person and think "function" you are going to respond in another way.

The future of chronic care depends upon a trinocular view; all three perspectives are critical to minimizing the accumulation of costs over time and across settings and in attaining quality outcomes.

A Trinocular View of Care

- **Illness**
- **High Tech**
- **Short Term**
- **Episodic**
- **One-dimensional**
- **Professional**
- **Cure**

- Health
- High Awareness
- Continuous
- Life-time
- Holistic
- Selfhelp/ Mutual help
- Prevention/ Delay

- **Function**
- **High Touch**
- **Extended**
- **Ongoing**
- **Multi-dimensional**
- **Paraprofessional / Family**
- **Care**

Chronic Care Networks

Once we adopt this trinocular view, it is important to begin to evolve what the NCCC calls "Chronic Care Networks" (CCNs). A CCN is a personcentered, community-based, systems-oriented alliance

among providers who serve a common group of people with serious and persistent chronic conditions. Problems like Alzheimer's, heart disease, diabetes, arthritis, and chronic obstructive pulmonary disease become our primary concern, with roles, responsibilities, and authorities redefined to offer whatever combination of care is most cost effective to prevent, delay, or minimize the progression of disability through a condition's natural evolution. The focus is on managing care across time, place and profession rather than within predefined institutional structures. Relationships among care components are integrated to maintain a simple, seamless continuum of quality care.

CCNs are not necessarily independent, self-standing organizations, but are hospitals, physicians, nursing homes, home care providers who serve the same people in a defined community and who have a shared vision, common leadership, and integrated procedures. One might think about CCNs as PSOs with special care capabilities or specialized PSOs. They may also be special care networks used by HMOs, CMPs, and other third-party payers. They may operate under a single governance structure or they may not. Their primary focus is on how people function, rather than on issues of ownership. The major issue is how people work together across settings to achieve a common set of care objectives focused on problems of chronic disease or disability.

CCNs actually transform the nature of how we provide care in response to the natural evolution of chronic conditions instead of in response to a crisis event or simply a presenting problem that shows up at the front door. CCNs track the progression of conditions as they evolve over time, from pre-symptomatic issues such as smoking and stress, to disease manifestation such as high blood pressure and diabetes, to problems of diabetes, high blood pressure, and COPD, to the multidimensional and interdependent problems commonly seen among the frail elderly. If someone has an ongoing condition, CCNs continually ask: "Do we know where that person is in relation to the condition's evolution? Do we know what intervention is most effective to minimize that person's disability progression?"

Critical Components for Transforming Healthcare

To meet the healthcare needs of the next millennium, we need to focus on integrating the following critical organizational components that guide and support Organizational behavior.

Integrated Governance/Management

Integrated governance links key executives, leadership, and network personnel in support of a common mission. People in healthcare today find themselves increasingly encumbered by governing boards who function out of old paradigms. Many who sit on board have become experts in managing a hospital or a nursing home, component parts of our healthcare system. As a result, they frequently think in terms of buildings instead of problems. Their decision making is bounded by the place they govern rather than the start point and end point of the problem to be addressed.

If we are going to change the nature of healthcare over time, it is imperative that we re-define governance structures to reflect a new vision, where everyone who is important to solving the problem sits at the table. We need to ensure that those who serve on these boards are conversant not only with the medical components of healthcare, including hospitals and physician services, but also with home healthcare, nursing home care, and the spectrum of home and community-based services. We must become more conversant with the problems of Alzheimer's, arthritis, and heart disease as well as with those of business, financing, and facilities. We need to have staff whose roles and responsibilities extend beyond simply managing programs and functions within predefined places. We need health leadership that cuts across settings to enable continuity of care throughout a condition's natural evolution. We need training and education for our healthcare professionals across settings that builds a sense of team,

focused on the problems of people served.

Until we change governance structures, until we change how we organize, staff, and manage, we are not going to achieve the kind of outcomes we need.

Integrated Care Management

The goal of integrated care management is for care provided in different settings at different times and by different professionals in the network all to support common client and system goals. To do this, we need to establish seamless continuums of care, including the full spectrum of primary, acute, and long-term care services. In most cases healthcare professionals define continuum of care in the context of place, for example, establishing a continuum from home to nursing home or from hospital to home. In chronic care the continuum must follow the person. It is important to define the concept of continuum in relation to how a given set of conditions evolves over time. All the major pieces must be in place, but their relationship to one another must respond to the changing dynamics of the person being served.

We must get away from simply connecting the different places. We must avoid thinking about admissions and discharges between staff who serve the same person and start thinking about helping people make a transition from place to place as their needs evolve across time and setting. We need to develop single plans of care whereby all staff who serve the same person adopt common approaches that prevent, delay, or minimize disability progression, regardless of who provides the care.

We must develop what we call extended care pathways (ECPs). ECPs are not simply care approaches within a setting. ECPs facilitate integrated care by applying a single approach to care throughout the entire course of a condition's evolution. The starting point for care planning is risk factors associated with next-stage disability progression, not admission to a given facility or program. The ending point is death or problem resolution, not discharge. Extended care pathways enable providers to be more than a patchwork of admissions and discharges-to be a team of providers addressing a common set of problems in pursuing a common set of cost and quality objectives. Chronic disease defies the logic of facility-based planning, and we must establish care planning accordingly.

Integrated Information

To prepare for the needs of the 21st century, it is critical that we improve our use of information technology. We need to establish communication systems that allow providers in all settings to share information about clients, costs, and operations. Integrated care requires information systems to be integrated so that people responsible for making administration, finance and care decisions for a common clientele can see the whole picture of what is being done for whom, in addressing what conditions, at what cost, and to what effect.

The capacity of existing information system technology is far beyond how we use it today. Our current uses are too bounded by outmoded structures. No one can tell us the true cost of any chronic disease or disability today. We make assumptions about the costs of care. We aggregate costs. We organize our information systems around settings so we know the costs of pieces of care, but have only a peripheral sense of the cumulative cost of care for a person as that person's condition evolves over time. We organize information systems around functions and setting, using them to maximize billing, simplify record-keeping and track outcomes-specific institutions and programs. We need to find new and creative ways of linking our independent information systems across all settings and care providers who serve the same person, either at the same time or sequentially.

If we don't connect cost, quality, and patient information across settings and over time-and, in most cases, we don't-we cannot make reasonable judgments about what combination of care is most effective. We can determine what is most cost-effective for a place, a treatment, an episode, or an event, but we don't know what is most efficient or effective in providing care over an extended period of time. We simply must develop new approaches that empower us to bring disparate organizations and information together to make quality decisions.

Integrated Financing

Building effective health systems for people with chronic illnesses requires changing the financing incentives and infrastructure for managing care. Current healthcare reform is mired in simply ratcheting down costs, leaving our current provider structures in place. If we simply lower costs in each healthcare setting, we think we will save money over the long term. The truth is we have no sense of what this ratcheting of costs does cumulatively; it may be that as we shrink costs in one place, we increase costs in another, or delay costs for another time. Care needs may even require a whole new provider structure, one that is more person-centered and less institutional, one that is more community-friendly and less bureaucratic.

The goal of integrated financing is that all components of network financial management support integrated, appropriate, and cost-effective care delivery across time, place and profession, regardless of who provides the care. Key elements of integrated financing include pooled, primary, acute, and long-term care financing; network contracting with provider flexibility to move dollars to whatever combination of care is most cost effective for community-based networks or teams; capitated, risk-based financing; outcome-based accountability; and integrated cost accounting strategies that track costs across settings and over time.

If we are going to redesign our service delivery environment, if we are going to reengineer care in keeping with problems of the 21st century, it is vital that the purchasers-federal and state governments and other private insurance carriers-and the payers-whether HMOs or insurance companies acting as third party payers on behalf of purchasers or PSOs with providers sharing risk under direct Medicare risk financing-all see themselves as part of the same team. We must realign incentives to enable collective action to prevent, delay, or minimize disability progression, regardless of the legal basis for how we govern.

Integrated Policy

In addition to transforming our service delivery environment, it is important that we also reengineer the public administration of healthcare programs in light of future rather than historical needs. While the delivery of care is local, the financing of care is national. Whether we like it or not, the majority of healthcare is financed by government. For most of us, the majority of our care, near the end of life, will be financed by Medicare or Medicaid. And, while most Americans believe in private institutions, we rely on government to insure equity and quality and to help us fill the gaps in our private insurance, particularly if we are no longer able to finance the significant ongoing cost of long term care. We also rely on government to stage the debate of healthcare reform.

The emergence of chronic disease and disability as America's number one healthcare problem sounds a clarion call for national leadership, to create a sense of understanding and urgency regarding the need for systems transformation in the care of people with serious and disabling chronic conditions.

Currently, the administration, financing, and oversight of government sponsored programs locks in place

a fragmented, institutionally-biased, reactive, and cure-oriented approach to care. Policies and procedures for Medicare, Medicaid, the Veterans Administration, and a host of other programs available to people at various stages of disability, frequently provide incentives to third-party payers and providers to maintain antiquated operations. Rules and regulations provide disincentives for serving people with chronic conditions and for using collaborative disability prevention methods. They restrict innovation and retard the evolution of a person-centered, community-based, systems-oriented approach. They encourage cost shifting between programs, federal and state governments, and service providers. Again, it is not because of people with evil motives or incompetence; it is simply that we work within outmoded operating structures.

Effective care of the chronically ill requires that we become more cognizant of the future prevalence rates for major chronic conditions and the projected costs associated with various disease and disability trends. It requires that we create a national agenda to reduce the projected incidence and prevalence of chronic conditions through better care intervention. We must shift from an emphasis on reducing costs for defined programs to exploring what incentives and oversight functions can enable people in the private sector, working within defined communities, to establish a new generation of care in keeping with the nature of chronic illness.

Legislation passed in the Balanced Budget Act of 1997 created a foundation for reform, but if we are to meet the healthcare challenge of the next millennium we must do more. In order to effectively address problems of the 21st century, public policy must focus more on the problems of people than on payment to third-party payers and providers, more on defining incentives for achieving predefined outcomes than on maintaining predefined structures and procedures through rules and regulations which are rooted in outmoded methods of operation. In particular, we must focus on problems of chronic disease and disability.

We are not going to meet the healthcare challenges of the year 2000 and beyond until we standardize Medicare, Medicaid, and other public programs for the chronically ill. We are not going to improve healthcare and make it truly cost-effective until we streamline rules and regulations so that providers do not have to respond to multiple and different requirements serving the same people over time. We are not going to achieve long-term cost savings and improve quality outcomes until we move out of component-based policymaking for hospitals, physicians, nursing homes, and other provider groups, and create incentives and oversight structures that enable providers to offer whatever combination of care is the most cost effective. We are not going to preserve the Medicare Trust Fund and preserve the trust with those it serves until we zero in on problems of chronic disease and disability, reduce the swell of prevalence rates, and adopt more person-centered, community-based, disability prevention-oriented approaches to care.

To meet the future chronic care challenge, we must align roles and responsibilities for States and federal agencies who administer Medicare and Medicaid to stop cost shifting, reduce administrative burden, and enable collective decision making in support of common care objectives. We need to redefine public administration in relation to the ongoing, interdependent, disabling, interpersonal, and multidimensional problems of chronic disease and disability. We need policies that cross time, place, and profession with aggregate results, not results tied to specific places and circumstances. We must establish a national chronic care agenda for the 21st century that seeks to contain costs through better care intervention, that seeks to reduce cost by reducing demand, that seeks to do whatever is needed to bring quality and cost containment into common alignment, with support for whatever proves to be most cost effective for improving the overall health and well being of our citizens, regardless of how it impacts institutions of historical precedence.

Reengineering Managed Care

To transform healthcare in preparation for the needs of the next millennium, we must also reengineer managed care. Managed care financing can work positively for people with chronic diseases and disabilities. Yet there is evidence that current managed care financing arrangements may actually hinder the care of people with chronic diseases and disabilities. The problem is not managed care as a concept. The problem is managed care as it is currently practiced.

Managed care involves paying for a defined set of benefits for individuals who enroll in a defined health plan and living within a defined community. The assumption is that in risk based financing there is a fixed dollar amount that can be used to respond to a full array of problems, with the flexibility to send dollars to whatever combination of care that is most cost effective. There are built-in incentives for pursuing a disability prevention strategy, for transforming our healthcare environment to achieve better outcomes on behalf of government and employers as well as the people served. There is the potential for enabling compatibility between cost containment and quality of care objectives.

Unfortunately, our obsession with managed care financing has blinded us to the power of managed care to contain costs through use of new and improved care methods. In far too many cases under current managed care financing arrangements, managed care organizations function simply as a third party payer. Prevailing managed care companies, functioning as third-party payers, take 15 to 20 percent of revenues received off the top of a particular allocation to cover their own predefined administrative costs. Then they write a series of contracts with hospitals, nursing homes, and home health agencies under separate agreements, using a variety of arrangements that produce disincentives to coordinate care or to pursue prevention strategies. There are frequently disincentives for targeting care for the seriously ill and virtually no incentives for collaboration. The incentives are for a provider to batten down the hatches, close the door on collaboration, and do whatever is most beneficial for their own bottom line, without regard for or even awareness of the cumulative effects of independent decision-making.

Until we focus on the fundamentals of managing care through evidence-based decision-making, as well as leveraging use of capitated financing to reduce cost, we are not going to achieve the cost and quality goals we all desire. We need to refocus financing to support integrated delivery networks and abandon blind reinforcement of component-based management. We need to provide incentives for groups of providers targeting chronic conditions of major concern. We need to align financial incentives among providers functioning in the same care network so that financing can shift from one program to another, with all providers in the network functioning in favor of whatever produces the greatest collective good, whatever reduces costs and achieves better care outcomes over the long term.

Preparing for the Next Millennium

A new care reality is not going to happen over night or by itself. Change, particularly system change, is an ongoing process. It requires people throughout the healthcare industry-policymakers, insurance companies, health systems administrators, physicians, nurses, social workers, and consumers and consumer advocates-to put on new lenses, with a commitment to work together under a new paradigm. It requires people to think outside of the mental constructs within which we work and refocus their attention on problems of chronic disease and disability. It requires everyone in healthcare to feel a sense of urgency about doing something different to increase our level of professional understanding of what is most critical for people to live a life of health and well being, not only for as long as possible, but with as much meaning as possible, throughout all phases of our life process.

Five tasks are crucial to moving this reform process forward:

1. Think systems.

Problems of chronic disease and disability are multidimensional, interdependent, and ongoing. Chronic care is a systems problem and requires a systems solution. While we must preserve the pieces of healthcare, our success, over the long term, is dependent upon our ability to make whole cloth out of disparate parts. It is not only about perfecting the pieces; it is about perfecting how the pieces fit together.

In a time of increased competition it is easy to become defensive, to build fences around what we know, to strengthen the fortresses of hospitals and nursing homes. "Do what we do now but better. Stay out of relationships; relationships are messy." Yet in the long run we do not succeed by standing alone or by pairing up with others just like us. Our success comes in establishing relationships with those who complement our skills.

It is important to remember that in chronic care the best way to compete is to cooperate. Success is dependent upon knowing how to work within disparate structures, how to celebrate diversity. It is not about building larger and larger hospital systems, larger and larger nursing home systems, larger and larger systems of primary care clinics. It is about bringing together the pieces of healthcare to serve a common population, with an eye to integrating care as chronic conditions evolve across time, place, and profession.

2. Focus our energy on the future.

These are very scary times. The current pace of change is faster than at any time in history. Change is more pervasive than at any time in history. The environment today is very unstable, and in times of instability it is easy to feel out of control, to find comfort in doing more of what we know.

The truth is the future is ours to define. We have, in part, already defined our own future by what we have done to date. Our bodies, our social institutions, our technologies are all a product of our collective invention. They have a life of their own. We can choose to ride the wave we have set in motion. We can try to stop it; reverse the course of history. Or, we can build on the strengths and weaknesses of our lot and create something new. We must establish clarity about the kind of world we want to live in and act on that vision of care, or it will be defined for us.

In many ways, healthcare today is like driving a car full of active people. Under these circumstances we have three primary options for where we focus our attention. We can focus on what we see in the rear view mirror, we can focus on the ruckus inside the car, or we can focus on the road ahead. If our symbolic car is healthcare, our view in the rear view mirror is defined by component-based healthcare, by specialized medicine, by actuarial tables, by rules and regulations of the past. Our view inside is one of chaos, pressure to produce more with less, to generate revenue, to increase market share, to define life by new technology. The road ahead is less clear. Most know it will not be like the past, but until the fog clears, we are unsure. We are preoccupied by the ruckus in the car. We try to read the future, but given the fog, we look in the rear view mirror for guidance.

If we move forward with blinders, stay the course, perfect our current ships of state as they are, we may simply be polishing the Titanic. If we obsess over the present or peer too much into the past, we may drive off a cliff, for the trajectory of our actions is moving us in new directions. We can increase our chances for success only by recognizing that we are in control of our own destiny and by establishing clarity about where we want to go.

The assumption of NCCC members is that the goal of healthcare is to maximize the health and well being of those it serves, to enable the emergence of healthy communities. For the NCCC, the primary focus is on people who are at risk of affliction from problems associated with chronic disease and disability.

For NCCC members, as non-profit organizations, profit margin, authority, image, market share, and technological advancement are important but secondary. They are means to an end, not the end themselves. They are useful only if they help us get where we want to go. Our primary focus is on bringing meaning to the lives of people we serve by preventing the onset of chronic conditions, by minimizing their impact, if and when they become a problem, and by helping people find meaning, if and when the disabling effects of chronic disease and disability become pervasive in a person's life or the life of a loved one.

3. Bridge the boundaries of social institutions.

The starting point for this task is to stop throwing stones at others. The starting point is not to get government off our backs. The starting point is not to get management out of our face. The starting point is not to control how doctors and other care providers make decisions. The starting point is not to have clients become more responsible. The starting point is not about "them." It is about us.

It may seem that much of what is required lies outside our control. So we ask, "What can I do to preserve my autonomy"? or, "What can I do to retain control over the pieces I already own"? However, in chronic care, the most important issues are not about control, but about how the pieces of healthcare function in relation to one another. It is not about buying and selling. It is about building relationships in service of people with chronic disease and disability.

We are not going to solve problems of chronic disease and disability until we understand that our future success requires us to celebrate unity amidst diversity. Policymakers, insurance specialists, health systems executives, and program managers, direct service providers, patients, and family caregivers are all in this together. Physicians, nurses, social workers, and other healthcare professionals are all on the same team. We are only going to achieve our vision of healthy communities by coming to grips with the fact that this is a team effort, a community effort, a national effort. As healthcare professionals we have a collective responsibility to find solutions together.

Once we view this as a team effort, we can assess the readiness of our institutions to become the institutions of health and wellness for all people, with special skills in preventing, delaying, or minimizing the impact of chronic disease and disability as people seek to find meaning in their lives. We can look at the structures and procedures for how we make decisions, how we function, and change them to be more effective in pursuit of our social mission.

4. Build a new infrastructure for decision making.

Again, the problems of today are not about incompetent people. They are about ineffective systems. They are about how our organizational structures and procedures, our new technologies, strengthen or impede our ability to address problems of chronic disease and disability. Where they impede our progress, we must change them. Where they enable our progress, we must strengthen them. We must change the structures and procedures for administering, financing, and delivering services for the chronically ill commensurate with the nature of chronic conditions. We must put on the lenses of a multidimensional, interdependent, disabling, interpersonal, and ongoing problem and establish a new infrastructure for managing money, information, and care.

In assessing the infrastructure of our social institutions we must view them from both a vertical and a horizontal perspective. From a vertical perspective, it is important to assess the effectiveness of relationships that exist between federal and state government, between government and third-party payers, between third-party payers and providers, between providers serving the same community, and between providers and recipients of care. All elements of the healthcare industry are involved in making decisions about problems of chronic disease and disability. Success requires that the structures and procedures used by the spectrum of healthcare institutions be properly aligned around a common set of assumptions about what is most important for enabling our health and well being, given our focus on problems of chronic disease and disability.

Within each community we need to assess how providers, who serve many of the same people either at the same time or over a period of time, enable or impede one another in achieving a new vision of care. How is it that hospitals, physicians, nursing homes, home care providers, community-based programs, assisted living providers, public health officials, enable or impede one another to strengthen the health and well being of those served?

In this analysis, it is particularly important to pay attention to how we:

- identify people at risk for problems of chronic disease and disability
- define what services we will make available and at what time
- collect, share, analyze, and communicate information
- choose financial incentives, structures, and procedures
- delegate or retain authority
- define roles and responsibilities for decision-making.

The final task is to act, to get on with it. How people proceed will vary from one organization to another. However, regardless of the setting, it is critical that everyone:

- maintain some commonality of vision
- empower internal champions to assume a leadership role in charting a course of action
- ensure that the necessary commitment exists, from the top, with senior executives in charge who possess skills in managing complex relationships
- align themselves with others, vertically and horizontally, to build relationships of importance to chronic care integration
- create financial incentives and investment for systems transformation
- maintain a sense of mutual respect and understanding
- develop a blueprint for change
- commit to getting on with the task at hand, with tenacity and purpose for establishing the culture, tools, and technology for effective action.

Chronic disease and disability is the number one problem in healthcare. More money goes to caring for problems caused by chronic conditions than to any other problem. This will be true well into the 21st century, and the pervasiveness of the problem will only become more pronounced. We need to refocus our attention on the problem at hand and get on with the process of change.

THE DISABILITY PREVENTION PROCESS

The stages of disability, as defined by the Institute of Medicine (1991), are:

Pathology: The interruption of or interference with normal bodily processes or structures as a result of cellular and tissue changes caused by disease, infection, trauma, congenital conditions, or other agents.

Impairment: A discrete loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function, including all losses or abnormalities caused by all forms of pathology, not just those attributable to active pathology. Also includes pain.

Functional Limitations: Restriction or lack of ability to perform an action, or limitations on activity in the manner or within the range considered normal. All functional limitations result from impairments, but not all impairments lead to functional limitation.

Disability: The inability or limitation in performing socially defined roles and tasks expected of individuals within a social and physical environment.

Important Definitions

The major driving factors in our healthcare reform effort are managed care and integrated delivery systems. People frequently mix these concepts and the terms connected with them. The NCCC uses the following definitions.

Serious and Disabling Chronic Conditions

A serious and disabling chronic condition is one or more biological or physical conditions which are likely to last for an unspecified period of time, or for the duration of a person's life, for which there is no known cure, and which may affect an individual's ability to carry out basic activities of daily living and/or instrumental activities of daily living. Such conditions may include, but are not limited to: Alzheimer's disease and related disorders, arthritis, cancer, cerebrovascular disease, depression, diabetes, emphysema and bronchitis, chronic obstructive pulmonary disease, hip and other fractures, hypertension, ischemic heart disease, multiple sclerosis, Parkinson's disease, peripheral vascular disease, renal disease, and other related conditions.

Chronic Care

Chronic care includes the entire spectrum of services required by people with serious and disabling chronic conditions, including primary prevention, primary care, acute care, long term care, pharmaceutical care, community care, supportive housing, alternative therapies, and other interventions that prevent, delay, or minimize disability progression associated with the multidimensional, interdependent, disabling, interpersonal, and ongoing nature of chronic conditions.

Managed Care Financing

A healthcare financing strategy that requires providers to function under a fixed dollar amount, in providing services to a defined population enrolled in a defined health plan. Medical care is provided through staff, group, or independent practice associations. Financing options include capitated and global budgeting with providers reimbursed through discounted rates, per member rates, per case rates, specialty, bundled, or comprehensive pooled financing arrangements.

If you have seen one managed care organization, you have seen one managed care organization; managed care organizations can be extremely diverse. What is important about the NCCC approach to managed care is to think about managed care financing as strategies *within a fixed dollar amount*,

providing care to a defined population enrolled in a defined health plan. This is contrary to a fee-for-service strategy where money is paid to a particular providers for specific care. Managed care provides, in advance, money for a specific group of people to pay for a specific set of benefits.

Integrated Delivery Systems

A group of providers working together under a common governance arrangement in serving a defined population. Integrated health networks may include the full array of prevention, primary care, acute care, transitional care, and long-term care services. IDSs increasingly function under managed care financing arrangements and may include direct administration, a health plan and financial administration.

Integrated delivery systems (IDSs) focus on care. IDSs have resulted, primarily, from managed care financing initiatives and are, significantly, driven by managed care financing initiatives. Organizational environments are beginning to blur the boundaries between financing and healthcare delivery.