

Check List for Chronic Care Reform

A Call to Action

People with chronic conditions such as heart disease, Alzheimer's disease, lung disease, and depression are healthcare's largest, highest-cost, and fastest-growing service group. Over 125 million Americans have one or more chronic conditions.¹ The number of Americans with one or more chronic conditions is projected to increase by more than one percent each year through 2030.²

The personal and societal costs of this problem are staggering. Seventy-eight percent of all medical costs are for people with chronic conditions.³ Spending on people with chronic conditions is projected to double between 2000 and 2010.⁴ The 20 percent Medicare beneficiaries with five or more chronic conditions account for two-thirds of Medicare spending.⁵ Nearly 30 percent of all Medicare expenditures are for people dually eligible for Medicare and Medicaid, and almost 50 percent of all Medicare beneficiaries with Alzheimer's disease are dually eligible for Medicare and Medicaid.⁶ In 1999 at least 7.4 million working-age Americans with chronic conditions lacked health insurance.⁷ Over 45 percent of health care expenditures for non-elderly employees are for people with three or more chronic conditions.⁸

Unfortunately, most prevailing financial and regulatory incentives and structures fail to account for the multi-dimensional, interdependent, disabling, and ongoing nature of chronic disease and disability. This is true for private as well as public insurance programs. For example, Medicare and Medicaid, the principal payers of chronic care services, are solidly rooted in a segmented, crisis-oriented, acute care model; even though the vast majority of Medicare and Medicaid expenditures are for care of people with chronic conditions. In fact, most of the Medicare population may actually be uninsurable, even though it is organized as a public insurance program. This is in large part due to the pervasive presence of chronic illness among Medicare beneficiaries. For example, Nobel laureate Kenneth Arrow says that "among people who already have chronic illness, or symptoms that reliably indicate it, insurance in the strict sense is probably pointless."⁹

Undoubtedly, hospitals and physicians, and other acute care benefits are of major importance to people with chronic conditions. However, while these "care components" are important benefits; the cost and quality of chronic care will remain sorely inadequate until the manner in which care is financed, administered, and delivered is restructured to be more in accordance with the nature of chronic disease and disability. For example, at their simplest level, chronic conditions are:

- *Multidimensional*—yet most health care insurance and delivery structures focus almost exclusively on medical issues. They frequently ignore the nutritional, functional, personal and environmental issues involved.

¹ Anderson, Gerard. Presentation at the 13th Annual Conference of the National Academy of Social Insurance, Section IV, Washington, D.C., January 25, 2001.

² Shin-Yi and Green, Projection of Chronic Illness Prevalence and Cost Inflation, RAND, October 2000.

³ The Household Component of the 1996 Medical Expenditure Panel Survey (MEPS), sponsored by the Agency for Healthcare Research and Quality.

⁴ Zhang N., Wu, A., Weller, W, and Anderson, G. Unpublished data on the prevalence of chronic conditions. CMS. National Health Care Expenditures Projections: 2000-2010. CMS Web site, 2001.

⁵ Partnership for Solutions, Medicare Standard Analytic File, 1999.

⁶ Health Care Financing Administration, data from the Medicare Current Beneficiary Survey, 1996.

⁷ Reed, Marie C., and Tu, Ha T., *Triple Jeopardy: Low Income, Chronically Ill and Uninsured in America*. Issue Brief No. 49, February 2002. Washington, D.C.: Center for Studying Health System Change.

⁸ Johns Hopkins, Unpublished Report on Analysis of Claims Data for Large National Employer-Sponsored health Plan, 2003.

⁹ K J. Arrow, "Uncertainty and the Welfare Economics of Medical Care", American Economic Review 50, no 5(1963) 941-973.

- *Interdependent*—yet most health care policy and practice is organized around care provided by separate programs and providers, even when people need care from multiple providers, either at the same time or in direct sequence to one another.
- *Ongoing*—yet most health policy is heavily focused on responding to crisis events and financing discrete “encounters,” without regard to the progressive nature of chronic illness.
- *Disabling*—yet most policy and practice focus primarily on the management of disease.
- *Interpersonal*—yet health policy frequently ignores the interests of people to be served, particularly in regard to their interest in simple access to quality care, for being more in control of care decisions, and in wanting to receive care in a place that can help them maintain their independence and dignity.

This discontinuity is not only deeply imbedded in most health policy—it is also rooted in the infrastructure used by payers and providers in managing money, information, and care. Insurance benefit design, payment methods, financial incentives, oversight structures, contracting arrangements, information systems, and clinical interventions are all inconsistent with the nature of chronic disease and disability. Health care research, training and education are also deeply rooted in an antiquated approach to chronic illness care.

Clearly, there is a newfound interest in chronic care reform. In the last two years, a number of national organizations have produced major reports that identify chronic care reform as a top priority.¹⁰ In the spring of 2003, both houses of Congress approved major Medicare reform legislation that includes provisions specifically focused on improving care for people with chronic conditions. While these changes hold some promise for improving chronic illness care; the vast majority of market forces continue to reinforce an outdated approach to serving people with chronic disease and disability. Under any new Medicare legislation, both traditional Medicare and new competitive financing models will most likely continue to underpay for medically complex beneficiaries and retain incentives for plans and providers to avoid people with complex care needs. They will continue to reinforce the use of reactive, episodic, institutional, component-based models of care. They will continue to encourage most health care executives to adopt and maintain a short-term, bottom-line, bunker mentality to strategic management.

The fact of the matter is—people with serious and disabling chronic conditions are healthcare’s largest, highest-cost, and fastest-growing service group. It is nearly impossible for any health care executive to ignore the impact that people with chronic conditions have on their work. As a result, it is imperative that all people with chronic care responsibilities—policy makers, insurance executives, providers, and consumers—make every effort to move beyond talk and establish new operating methods that are more in keeping with the nature of chronic disease and disability. It is critical for people to rise above their immediate, short-term self-interest and recognize the interdependence of their decision making. It is vital, from a quality and a cost perspective, for all people concerned about the future of chronic illness care to:

- Establish chronic care reform as a matter of priority.
- Empower consumers to become more focused on and involved in chronic care issues.
- Adopt new technologies that are responsive to the multi-dimensional, interdependent, and ongoing nature of chronic disease and disability.
- Think long-term, but pursue short-term efforts in accordance with a new vision of the desired future.
- Avoid the trappings of old culture and the power of preserving the status quo where efforts may or may not be relevant to long-term cost and quality considerations.
- Think more about the nature of their relationships and less about preservation of internal operating systems that impede the ability to prevent, delay, or minimize disease and disability progression across time, place and profession.

¹⁰ The Institute of Medicine, the National Academy of Social Insurance, the Progressive Policy Institute, the World Health Organization, and the Health Care Assembly have all adopted policy positions that call for chronic care reform.

Chronic Care Checklist

The following checklist is intended to help purchasers, payers, providers, and consumer organizations establish new policy, payment, management, information, and delivery systems to more effectively address problems of chronic disease and disability. They are based upon over a decade of experience by members and staff of the National Chronic Care Consortium, who since 1991 have come together to develop practical but innovative solutions to chronic illness care. They seek to help health care leaders uncover the operational impediments that are most onerous in serving people with chronic conditions and to establish new short-term interventions that are most important for achieving long-term quality and cost objectives. It gives particular emphasis to the needs and interests of those with multiple complex care needs, as it is understood that current operating methods are most troublesome for this high-cost and high-use service group.

The chronic care checklist is organized around eight principles for establishing a condition-based, person-centered, systems-oriented approach to care for people with chronic conditions. This experience-based checklist does not contain answers to the complexity of issues faced by people involved in chronic illness care. Rather, it is intended to serve as guideposts for individually designed chronic care reform initiatives.

1. All people are fully empowered to address issues of chronic illness.
2. A complete and flexible set of benefits and services is available and accessible.
3. All industry methods are responsive to the nature of chronic illness.
4. Care providers who serve the same person offer complementary support.
5. Related administrative structures and procedures support effective chronic illness care.
6. Financing structures and incentives support effective chronic illness care.
7. Public and private policy and administrative oversight enable purchasers, payers, providers, and consumers to optimize cumulative cost, quality, and satisfaction outcomes.
8. Training, education, and research enable purchasers, payers, providers, and consumers to successfully implement a customer-driven, systems-oriented approach to chronic illness care.

This checklist is built upon work done by NCCC staff and members in creating SASI, a self-assessment for systems integration tool.¹¹ The set of indicators will continue to change as new learning is acquired through scientific research and the practical experience of those involved in day-to-day operations.

1. All people are fully empowered to address issues of chronic illness.

This principle rests on the assumption that people at risk of or afflicted by chronic illness must be fully informed about issues of importance to them and that they must be in full control of decisions about their own health. Key elements include:

- 1.1 All people have access to the most advanced chronic illness care information for all types and degrees of disease and disability progression. This includes information about symptoms and risk factors for disease onset and progression, including those related to genetic predisposition, medical history, and current environmental circumstances.

¹¹ The SASI tool was designed to enable primary, acute and long-term care providers who serve a common group of patients and families with chronic conditions, such as CHF, COPD, hip fractures, strokes, and Alzheimer's disease, to align their operating methods in keeping with the needs and interests of people with multiple, complex care needs. The tool was developed and tested in multiple settings and over many years to facilitate planning for systems change. The SASI indicators have been modified in order to take in account new learning on issues of importance in care of people with chronic conditions and issues of importance in the establishment of health policy and the education of new health care professionals.

- 1.2 All people have access to the most current information available about best practice methods including tools for assessing quality and selecting providers.
- 1.3 All people seeking care for chronic conditions are fully informed of available benefits, including how to obtain services, as well as information on cost, quality, and satisfaction with reference to available providers.
- 1.4 All people have access to self-care services and self-care technologies to optimize their health and well-being.
- 1.5 All people seeking care are fully informed of care options and fully participate in making decisions about care interventions, with all parties appropriately accountable for decisions made.
- 1.6 Family caregivers are informed, trained, and given emotional support in their efforts to help their loved ones deal with chronic conditions. This includes respite care and assistance in making financial and legal decisions.
- 1.7 Healthcare professionals complement, rather than supplant, the self-directed activities of people served.
- 1.8 Care is provided at the time and in the place that offers the greatest freedom and personal comfort that a person's condition will allow.
- 1.9 All people are guaranteed the right to privacy, with full knowledge of and control over what information is retained and shared.

2. A complete and flexible set of benefits and services is available and accessible in every community.

- 2.1 All people have access to a full array of healthcare services, including primary care, specialized medical care, acute care, transitional care, home health care, rehabilitation services, residential care, community-based long-term care, adult daycare, pharmacy services, palliative care, complementary care, assisted housing, and supportive services.
- 2.2 Specialized chronic illness care services are available, including specialized diagnostic and disease management services, care management services, chronic illness care technologies, and adaptive devices.
- 2.3 All needed services are available to everyone regardless of race, age, sex, religion, nationality, sexual orientation, or income.
- 2.4 Services are available in the least restrictive and safest environment feasible.
- 2.5 Services are available when and where a person needs them, recognizing the limits of available resources.
- 2.6 The place where people live serves as the foundation for all service intervention.
- 2.7 All providers offer information about complementary services that maximize personal independence and well-being, regardless of who provides the care. People can access these complementary services from any provider setting.

3. All provider methods are responsive to the nature of chronic illness.

- 3.1 People seeking healthcare services are routinely assessed for their risk of chronic disease and/or disability and given special support, where appropriate, to optimize their health and well-being through optimum use of available resources.
- 3.2 Public health services target behavioral and environmental conditions that contribute to chronic illness.
- 3.3 Health screening and health promotion are available for early detection of high-risk problems and to prevent, delay, or minimize disease and/or disability progression.
- 3.4 All care providers are fully competent in chronic illness and chronic illness care.
- 3.5 Every assessment process, in every setting, takes into account the spectrum of biological, functional, psychosocial, and environmental aspects of a person's condition, as well as prior assessments performed by other care providers.
- 3.6 All care providers seek to prevent, delay, or minimize the onset and/or progression of disease and disability, in addition to responding to acute precipitating events and circumstances.
- 3.7 Where two or more chronic disease and/or disabling conditions exist at the same time, all care providers take into account the need to vary disease specific management methods and modify their approaches to optimize total care outcomes.
- 3.8 Special care arrangements are made for chronically disabled children, physically disabled adults, the frail elderly, the developmentally disabled, and people with dementia.

4. Care providers who serve the same person, either at the same time or in sequence to one another, offer complementary support.

- 4.1 All providers who serve the same person, either at the same time or in sequence to one another, have routine communication focused on optimizing their cumulative effect on quality, cost, and customer satisfaction.
- 4.2 All providers who serve the same person for a common problem use complementary approaches to care.
- 4.3 Assessment and care information for people who are served by multiple providers is standardized and shared in a way that enables care providers to work together to achieve a common set of care objectives while respecting privacy rights.
- 4.4 People who need services from more than one provider can move from one care setting to another with ease, with minimal repetition of information or inconsistencies in intake, assessment, and care planning methods.
- 4.5 An interdisciplinary care team specializing in chronic illness care is available to healthcare providers who offer care to people with multiple medical comorbidities, functional deficits, complex medical regimens, and a high level of mental health problems. This includes the availability of specialized assessments, care planning, care management, and care consultations.

4.6 Public health officials, healthcare providers, and social service providers work together to achieve compatible quality, cost, and satisfaction objectives.

5. Related administrative structures and procedures support effective chronic illness care.

5.1 Boards of payer and provider organizations responsible for chronic illness care include representation from people with expertise in chronic illness care.

5.2 People who sit on boards and who are responsible for the ongoing financing and management of healthcare are fully informed of state-of-the-art information about chronic illnesses and chronic illness care.

5.3 Decision support tools are used in making program allocation decisions that take into account the multidimensional, interdependent, disabling, interpersonal, and ongoing nature of chronic illness.

5.4 Management structures reward innovation, collaboration, consumer empowerment, disability prevention interventions, and the pursuit of excellence in chronic illness care.

5.5 Information systems are able to track care outcomes and cumulative costs over time and across settings for people receiving service from multiple providers.

6. Financing structures and incentives support effective chronic illness care.

6.1 Adequate financing exists for all needed services, with emphasis given to preventing the onset of disease and prevention of disease and disability progression.

6.2 Payment methods take into account cost variances in serving people with different chronic conditions and with varying degrees of disease and/or disability.

6.3 Financing and oversight are structured in such a way that people can receive whatever services or combinations of services will be of optimum benefit to them, within prevailing resource limits.

6.4 Financing methods reward the targeting of high-risk problems, team efforts in problem resolution, consumer empowerment, disability prevention interventions, and quality.

6.5 Methods are used to hold payers and providers accountable for fraud, abuse, and neglect without adversely affecting quality care providers.

7. Public and private policy and administrative oversight enable purchasers, payers, providers, and consumers to optimize cumulative cost, quality, and satisfaction outcomes.

7.1 The general public and public officials are aware of the major issues and trends associated with chronic illness care.

7.2 A national chronic illness care policy exists, with guidelines for achieving a new vision of care and with national objectives established to reduce projected chronic disease and disability prevalence rates and to achieve defined quality and satisfaction targets.

- 7.3 Federal and state government, corporations, and private insurers of chronic illness care services use compatible actuarial methods, payment methods, and financial incentives to optimize cumulative cost, quality, and customer satisfaction objectives.
- 7.4 All employers, unions, insurance companies, and state and federal government officials who provide direction and financial support for chronic illness care use compatible approaches to benefit design and compatible oversight methods that embrace principles of chronic illness care and optimize health value for all Americans.
- 7.5 All policies emphasize continuous improvement of health value, in the collective, with secondary concerns for any one-service industry.

8. Training, education, and research enable purchasers, payers, providers, and consumers to successfully implement a customer-driven, systems-oriented approach to chronic illness care.

- 8.1 Basic and applied research on chronic illness care is fully funded to monitor disease and disability trends; reduce the incidence rates of chronic disease and disability; and improve cumulative quality, cost, and customer satisfaction outcomes.
- 8.2 The public is given current information on chronic disease and disability trends and information about chronic illness care.
- 8.3 All healthcare students receive specialized training and education in chronic illness care, using the most advanced knowledge available.
- 8.4 Direct care providers have up-to-date information on interventions and combinations of care that are most likely to produce the best long-term outcomes for major chronic illnesses or combinations of chronic conditions.
- 8.5 All healthcare professionals receive continuing training and education in chronic illness care that incorporates their primary operational issues in implementing person-centered, chronic illness care, using the most advanced knowledge available. This includes evidence-based information about interventions that are most likely to produce the greatest overall health and wellness outcomes for the longest period of time.

Conclusion

For health care plans, providers and insurance carriers to survive and thrive, it is important to refine internal operating methods in accordance with prevailing market conditions. It is important to contain costs, maximize revenue, enhance quality, improve market share, and respond to consumer interests. Competition is fierce; pressures are intense.

Pressures are no less severe for policy makers. Every constituency seems to have a new and unmet need that must be addressed. Everyone seems to have “the right answer” that must to be implemented “immediately”. Everyone believes that his or her issue is MOST important. There never seems to be enough time to do anything. Everyone wants more for less.

To be a successful business executive or an effective public servant, it is important to address these prevailing concerns. It is important to adopt new technology and to implement best practice methods. It is important to contain the escalation of costs while adequately financing needed services and functions. It is

important to approve health policy that stabilizes funding for hospitals, nursing homes, or home health agencies; responds to pressures for a new prescription drug benefit; and to address problems of the uninsured. It is important to debate the relative merits of national health insurance versus private financing models, fee-for-service versus managed care, and competitive versus mandated benefit contracts.

However, in the midst of this market pressure and political discourse; it is also important for people to rise above the fray and begin to establish new operating methods that everyone knows are needed to improve care for people with serious and disabling chronic conditions. It is important to deal with long-term as well as the short-term considerations. It is important to change market conditions and public policies, where they are needed, as well as to respond to prevailing market and/or political opportunities.

Awareness and understanding of the chronic care dilemma is clearly growing. There is expanded discussion, in all healthcare sectors and across political parties, of the importance of a new approach to chronic care. This is true at the federal, state, and local levels, as well as among public and private leadership. There is also a remarkable degree of commonality in the principles that people see as important for improving cost and quality outcomes. However, problem resolution requires that concerned healthcare professionals move beyond talk.

We must reach across industry silos; across consumer, provider, and administrative interests; across purchaser and provider boundaries; and across political parties to find new ways to work together to establish a healthcare system in touch with the realities of the new millennium. We must create a sense of hope and renewal among healthcare professionals that we can change how programs operate in service of people with chronic conditions. We must look at our collective behavior and reengineer the infrastructure of healthcare as component partners in pursuit of a common vision of care.

These are difficult times, for sure. We are all faced with limited resources and pressures to do more with less. Current market and political conditions make it exceedingly difficult to see beyond the next quarter's financial statement, the next government budget cycle, or the next election. However, long term cost and quality objectives cannot be achieved unless we change the infrastructure for how we finance, administer, and deliver healthcare to be more in keeping with the nature of chronic disease and disability. Long-term quality, cost, and consumer satisfaction considerations are all dependent upon a condition-based, person-centered, systems-oriented approach to reform that is shaped by the nature of chronic illness rather than the antiquated structures on which these programs were established. The time to act is now.