Issue Brief

Perspectives in Disability Prevention

Cheryl Phillips-Harris, M.D.
Sutter/CHS

National Chronic Care Consortium

The terms "prevention" and "wellness" are increasingly common in both medical and lay literature. Yet the general assumption remains that these concepts apply to only a healthy, younger population. The term "prevention" triggers mental images of crying infants receiving vaccinations, of women waiting to receive mammograms, and of people following low fat diets to reduce the likelihood of developing a disabling disease. While each of these measures is important, people often believe that prevention has little, if any, role in the management of the frail elder or the person with a chronic disease. Prevention and wellness programs, however, are effective for all ages and population groups.

As medical technologies have advanced in the nineteenth and twentieth centuries, the burden of disease has shifted from acute episodes of illness (e.g., infections) to chronic diseases (e.g., arthritis, heart disease, diabetes). Chronic disease is now the leading cause of disability. Approximately 35 million Americans suffer from some disability (Pope and Tarlov, 1991). Chronic illnesses cause more than 30 percent of limitations in major functional activities such as dressing and grooming (Collins, 1993). The cost of chronic disease is also enormous, not only in terms of the healthcare dollars spent on traditional medical services, but also in terms of the cost for caregiver support and institutionalization and the consequences of losing functional abilities and independence for the individual with a disability. Arthritis, for example, is the nation's most common disabling condition and costs the United States more than $54 billion a year (Lumsdon, 1995).

The belief throughout American society is that "aging equals disease," and, therefore, sets an expected life course of progressive disability and frailty. This belief then sets the stage for a view of public health in which chronic disease is inevitable and the associated disability is merely an expected outcome.

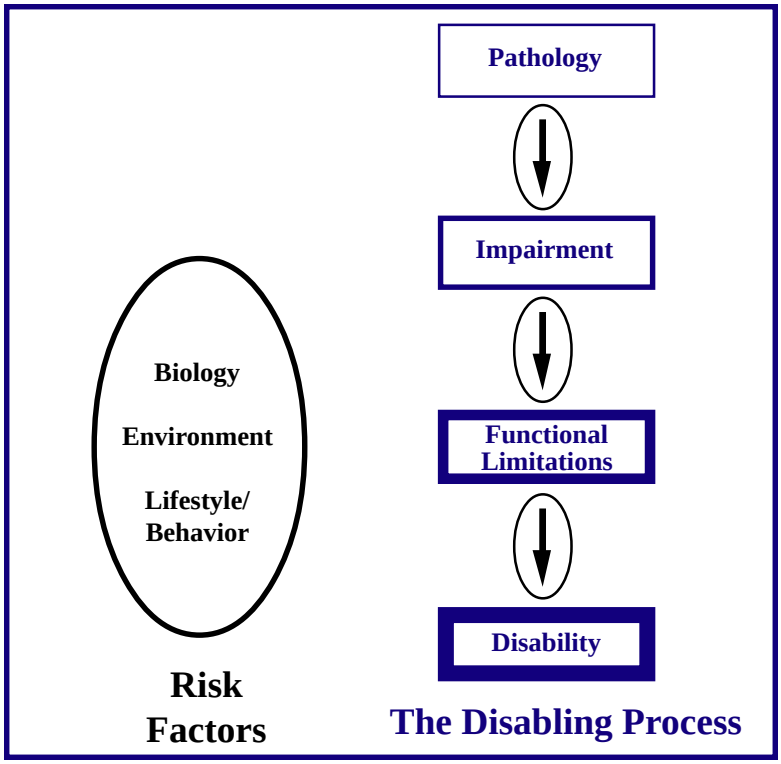
The Meaning of Disability

In order to define disability prevention, we must first understand the meaning of disability. Disability exists in a social context, as a result of functional limitations (due to a disease or condition) that affect the performance of an individual's expected roles and tasks in society. Not all functional limitations result in disability (e.g., a person with low pulmonary function may still be able to climb stairs). Conversely, similar disabilities may be caused by a variety of physical limitations (Pope and Tarlov, 1991).

Risk factors leading to disability can be described as an interplay between biological, environmental, and lifestyle factors. In the disability prevention process, disability progresses through four stages. These stages, as developed by the Institute of Medicine (1991), are pathology, impairment, functional limitations, and disability (see Figure 1). At each stage, providers and clients work to avoid, delay, or lessen the level of impairment, functional limitations, and eventual disability arising from the condition.

Disability prevention, therefore, includes identifying and modifying behaviors that contribute to disease and, hence, disability; early recognition of the biological manifestations of disease; and interventions that minimize the physical and social impact of functional limitations. Several initiatives have identified the older population as a target for preventive care and health promotion. Fifty-two percent of severely and chronically disabled people are over age 65. The workshop on Health Promotion and Aging (Pope and Tarlov, 1991) documents the benefits of several lifestyle interventions in modifying risk factors in the elderly, such as depression screening, exercise, good nutrition and smoking cessation programs. *The Healthy People 2000*, (National Health Promotion and Disease Prevention Objectives issued by the U.S. Department of Health and Human Services) explores a life course approach with defined goals of increasing the number of years of healthy life to at least 65 and decreasing the prevalence of chronic disease to no more than six percent of all people (Pope and Tarlov, 1991).

Figure 1: The Disability Prevention Process



Prevention Strategies

The goal of disability prevention is to maximize an individual's functioning, well-being, and quality of life while achieving optimum care and cost outcomes. Strategies for disability prevention are broken into three categories or levels, each corresponding to the four stages of disability progression shown in Figure 1.

Primary prevention is directed at disease avoidance. This includes educational and lifestyle modifications around issues such as substance use (tobacco, alcohol), nutrition and diet, exercise, heart disease, osteoporosis prevention, immunizations (e.g., for influenza, tetanus) and injury prevention. Several studies have shown reduction in disease morbidity and cost of care by simply providing annual influenza vaccines to at-risk population groups (e.g., frail elderly). Studies have also demonstrated under-utilization of these interventions by the "old-old" (over age 85) and by disabled individuals due to noncompliance with recommended interventions, lack of access to the services, physician failure to communicate the benefits of primary prevention for these clients, or a belief that behavior modifications cannot be made by the elderly.

Secondary prevention involves the early detection or early treatment of asymptomatic disease or disease in an early stage of progression. Perhaps the greatest area of disagreement in current literature is around the recommendations for cancer screening. While certain procedures (e.g., mammograms, pap smears) have proven cost-benefit ratios in specific populations, recommendations for other screening tests such as fecal occult blood and prostate-specific-antigen testing have ambivalent outcome data. There seems to be no consensus on cancer screening in the "old-old" or the frail where the likelihood is greater that the individual will die in the next five to seven years for reasons related to their chronic disease rather than from their occult cancer (e.g., prostate cancer screening in the 80-year-old with diabetes and heart disease). Secondary prevention services that are often overlooked in a frail population include risk screening for falls, incontinence, depression, polypharmacy, and other common geriatric syndromes. In these areas, small interventions can often have significant impact on functional status, independence, and a sense of well-being.

Tertiary prevention is truly the realm of chronic disease management. It includes rehabilitation services and early interventions to prevent functional decline through the progression of disease. The entire process of integrating chronic care delivery can be defined as tertiary prevention. Risk screening that is linked to a needs assessment process and a network of flexible, client-centered services is the foundation for such a model. The reengineering of case management into a system of care coordination across the continuum can become the vehicle of successful delivery. Tertiary prevention also includes the screening for and the provision of caregiver support and resources. It is estimated that 95 percent of personal care is delivered by 2.2 million informal caregivers (Folden, 1989). When tertiary services are not available, "social" problems quickly develop into "medical" crises that are dealt with, too often, in the acute care setting. Ultimately, this becomes extremely costly to the system, the providers, and the individual.

Successful disability prevention strategies (see Table 1) must be based on the

knowledge of risk factors, disabling conditions, quality of life factors, and the likelihood of contracting secondary conditions (e.g., decubiti ulcers, bladder infections). When appropriately applied, these strategies can lead to positive outcomes as measured by mortality, morbidity, functional status, quality of life, cost of care, and utilization of services.

Table 1: Range of Services by Type of Prevention

Primary Prevention	Secondary Prevention	Tertiary Prevention
1. Improvement of health habits: smoking, alcohol abuse, obesity, nutrition problems, physical inactivity, sleep problems	1. Screening: hypertension, diabetes, periodontal disease, dental caries, sensory impairment, medication side effects, colorectal cancer, breast cancer, cervical cancer, prostatic cancer, nutritionally induced anemia, depression, stress, urinary incontinence, podiatric problems, fall risk, tuberculosis (high risk), syphilis (high risk)	1. Rehabilitation: physical deficits, cognitive deficits, functional deficits
2. Immunizations: influenza, pneumovax, tetanus	2. Control of hypertension to prevent stroke	2. Caretaker support: introduction of support necessary to prevent loss of autonomy
3. Injury prevention		3. Pain control
4. Iatrogenesis[1] prevention		
5. Osteoporosis prevention		

Source: Adapted from P.S. German and L.P. Fried, 1989. "Prevention and the Elderly." *Annual Review of Public Health* 10:319-332

1 Iatrogenesis illness is a disease or condition acquired from treatment or a treatment setting.

Practitioner Issues

The focus on chronic disease is shifting from interventions aimed at a cure-oriented approach to illness to those aimed at limiting disease progression. Physicians and other providers often overlook prevention when trying to "manage" the complexities of chronic disease; or worse, they believe such interventions are "wasted" on the elderly population. Also, practitioners are often constrained by organizational structure and financing systems. For example, primary care physicians are expected to listen, diagnose, develop a treatment plan, and educate their patients within a 15 minute office visit. This leaves little time for nonmedical activities such as counseling.

All providers and practitioners need to have easy access to information on the risk factors and characteristics of their patients (e.g., as collected through valid and simple risk-screening tools). Disability prevention needs to be individualized by taking into account this information an incorporating it into patient problem lists, clinical databases, and care pathways. In the ideal interdisciplinary team approach to chronic disease care, much of the coordination and follow-through for prevention can be done by nonphysicians. In fact, case management can then move beyond the traditional roles of discharge planning and utilization review to care coordination that incorporates the concepts of disability prevention into the plan of care across the continuum.

Practitioners also need to periodically evaluate interventions to better meet the changing needs of the client. Initial interventions and subsequent evaluations need to include consideration of the multidimensional needs of clients (environmental, social, economic, and other nonmedical variables in addition to medical needs) for effective disability prevention. Interventions that are integrated into a client's lifestyle are often most successful. Care coordinators can use proactive follow-up as a key monitoring tool. For people with multiple chronic conditions, the need to coordinate primary, secondary, and tertiary prevention is essential. Individuals often have more than one chronic condition. For example, of the 20 million people aged 65 and over who have arthritis, 16 percent also have heart disease, 48 percent also have hypertension, 11 percent also have cancer, and 11 percent have diabetes (Van Norstrand, Funer, Suzman, 1993).

Healthcare networks need to look for incentives that allow clinicians to practice disability prevention on an everyday basis. A feedback mechanism to inform clinicians on how well or poorly the interventions are performing, particularly in terms of cost and care outcomes, can be a useful monitoring tool, otherwise the value of interventions may not be apparent to physicians. Henry Ford Health System in Detroit, for example, has created a Resource Case Management system *(St. Anthony's Health Care Capitation Report,* 1995*)* that provides physicians with real-time data (rather than historical after-the-fact data) on their clinical and cost performance. This system tracks clinical and financial status of patients on a daily basis, which is then fed back to the physicians, enabling them to concurrently assess their performance in relation to various clinical care interventions. Physicians can use this information as an analytical tool to look at resources used to care for their patients.

Provider Network Perspectives

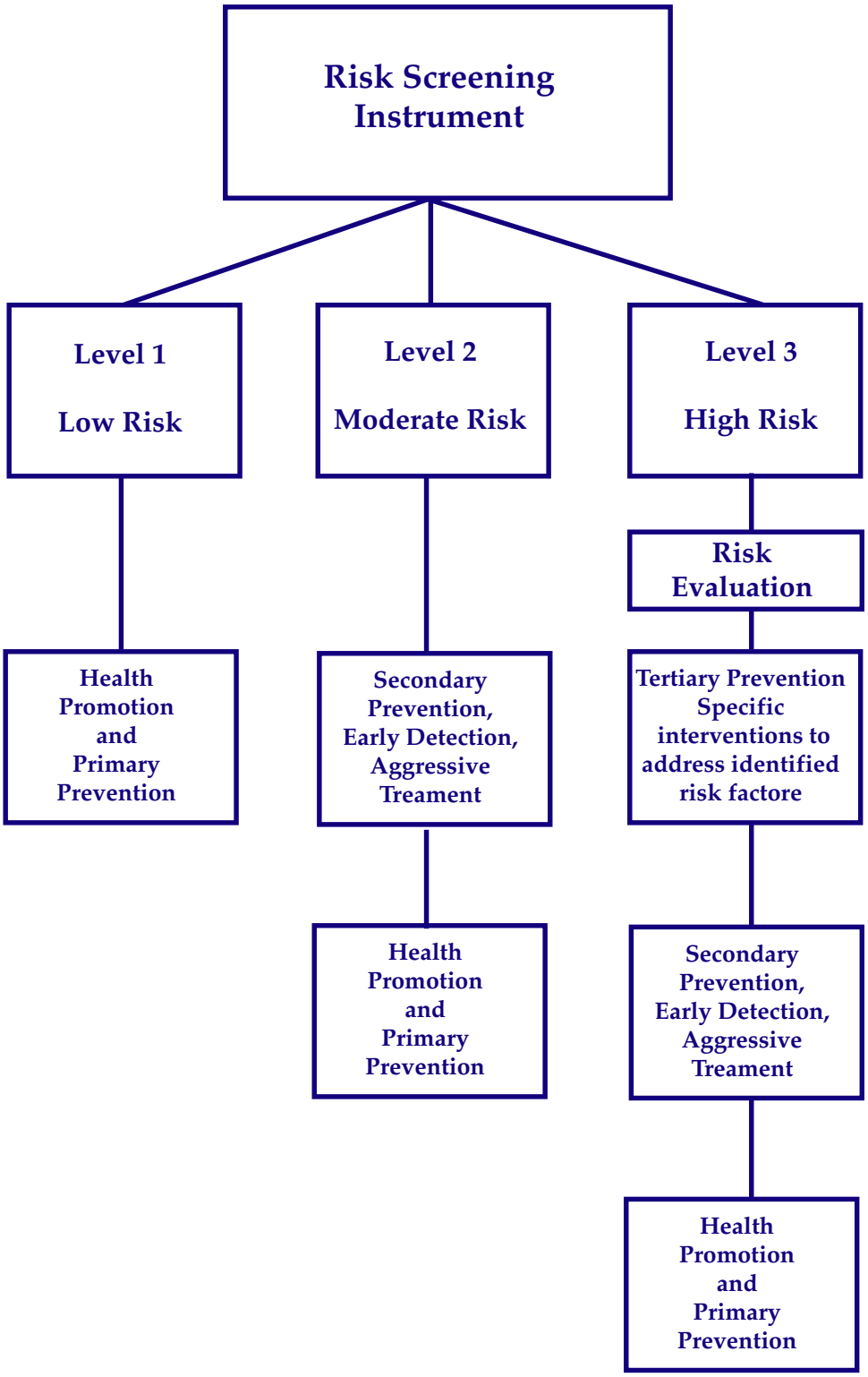
The NCCC defines a chronic care network (CCN) as a set of providers working together using integration strategies to serve a group of people with chronic conditions. A CCN could be an entire healthcare network or it may be a subset of a larger healthcare network. CCNs are in an ideal position to be proactive in creating and delivering disability prevention services for three reasons. First, they have access to entire enrolled populations. Through risk-screening methods, clients can be identified into risk groups (e.g., low, moderate, and high risk) and offered targeted preventive intervention services (see Figure 2). Second, CCNs have greater opportunities to develop information systems that can track individuals over time and across settings. Disability prevention is effective only when at-risk individuals can be identified, compliance to screening (either by the provider or individuals) can be measured, screening data can be tracked, and follow-up screening can be "triggered." Third, CCNs have access to all components of the continuum and, therefore, can offer a more flexible approach to providing prevention services at any level of care according to identified need. CCNs are also better able to follow clients across time, place, and provider.

Start-up concerns and challenges for providers include developing an organized risk-identification process and creating information systems that contain a patient database that is accessible to providers across settings and that includes individual risk factors, screening results, functional status, and chronic disease information. Networks need an infrastructure for information management to support implementation, monitoring, and evaluation of preventive services. These organizations face several barriers to developing a comprehensive system of prevention services. These include a lack of consensus on what to screen for and whom to screen, the cost of developing a prevention program, and the difficulty in demonstrating benefit in an often transient population when the investment made by one system may never be realized by the individual or organization. For example, in a Medicaid managed care program, the health plan's incentives and efforts may be minimized if the patient ultimately disenrolls (e.g., every 30 days) to join a new plan.

Once at-risk populations are identified, CCNs need an organized approach to provide specific interventions (e.g., immunization clinics, chronic disease educational resources.). These services have to be easily accessible to the individual and accountable to the primary physician for results. Perhaps the greatest misuse of prevention services are the frequently organized "health fairs" that offer a battery of tests, from comprehensive chemistry panels to carotid duplex studies. These tests are rarely targeted to people who are specifically at-risk for a given disease. At best, they are costly services that offer no improvement to outcomes. At worst, they uncover "abnormal" results that cannot be evaluated in the context of symptoms or history, and no one knows how or who is to follow-up with these results. Patients believe that they have had "a physical" and may neglect more productive and yet less glamorous interventions with their primary care providers, such as diet counseling, smoking cessation classes, or medication review.

CCNs also need the ability to track, over time, cost of care and clinical outcomes linked to prevention strategies. Then, they can provide the necessary evidence to demonstrate the benefits of prevention services that offset the initial financial investment for planning, implementation, and evaluation. CCNs can also serve as national laboratories to collect multifacility data necessary to create evidence-based standards for prevention in the chronically ill population.

Figure 2: A Risk-Screening Process and Disability Prevention Interventions



Client Perspectives

In order to create a successful disability prevention program, health networks must make services physically and organizationally accessible to clients (i.e. avoiding complicated referral steps or "authorizations"). Screening has to be linked to educational resources that can modify behaviors and thereby reduce the identified risk. When tertiary-level care needs are identified, services must be available to manage those needs or environmental factors. For instance, identifying that someone is at risk for falls does nothing to change the potential outcome (e.g., a possible fracture) unless that information leads to some intervention that reduces the risk of falls. From a client's perspective, interventions must be individualized and integrated into the flow of everyday life, otherwise they are perceived as irrelevant. It is estimated that friends and relatives provide two-thirds of all home care services to people with chronic conditions *(Case Management Advisor,* 1996). Caregivers need to be included in the plan as well, since they can often influence compliance.

Clients' needs differ according to their cultural backgrounds. Studies have shown that ethnic minority elders respond to a more holistic and less bureaucratic approach to disability prevention that encompasses mind, body, and spirit (Yee and Weaver). Disability prevention messages coming from relatives or peers, who can communicate effectively given their understanding of culture and language, may be more desirable. Understanding traditional health beliefs and using ethnic staff as cultural liaisons may also help clinicians effectively explain interventions and encourage compliance. Also, asking clients to repeat instructions can be a good way of measuring their comprehension level. Carondelet Health Care in Tucson, Arizona, which serves a significant number of Hispanic and Native American people, employs bilingual and bicultural community nurses who partner with culturally diverse clients at risk for chronic disease or disability and follow them along the continuum of care. Carondelet also uses "promotoras"—community health advisors who serve as culture "brokers" who identify people living in rural areas who are in need of care and encourage them to receive appropriate care.

The responsibility for disability prevention needs to be shared equally between a clinician and client. This is essential to achieving maximum benefits and plays a role in self-care. Self-care can make the interventions more relevant (to older adults in particular). Medical self-care is what people do to recognize, prevent, treat, and manage their own health problems (Mettler and Kemper, 1993). It can improve quality of life, help prevent complications, and help improve outcomes. In order for self-care to be effective, however, clients must receive sound information, training in self-care skills, and support to handle the interventions.

Outcomes studies on an arthritis self-management program developed by Kate Lorig and her colleagues at Stanford University have shown that program participants exhibit significant increases in disability prevention behaviors such as exercise and the practice of pain management techniques (Lorig, 1993). Participants also expressed a decrease in the level of joint pain because they felt they had more control over their symptoms. The Arthritis Self-Management Program is a twelve-hour course offered in senior centers, libraries, churches, and other community settings. The course content includes instruction on cognitive symptom management, patient/physician communication, and designing exercise programs.

Examples of Disability Prevention Programs

Several organizations have developed models of disability prevention that demonstrate the potential for service flexibility to meet the needs of the chronically ill.

The University of Pennsylvania's CARE (Collaborative Assessment and Rehabilitation for Elders) program uses geriatric nurse practitioners as care managers in an outpatient clinic. They provide an organized approach to functional assessment, need identification, and the provision of client-specific services for people over 65 with complex health problems who are still living at home. Clients are typically referred by their primary care physicians and receive an intensive, individualized, time-limited program of nursing, rehabilitation, mental health, social, and medical services several times a week. The average length of stay in the program is six weeks. Clients discharged from the program showed significant functional improvement as measured by Functional Independence Measurement scores (Evans, Yurkow, and Siegler, 1995).

Group Health Cooperative of Puget Sound has developed a model of care designed to prevent and manage complications of diabetes among its members. The program begins with an understanding of the dimensions of behavior change based on an assessment. A multidisciplinary team then provides client-specific educational resources, based on their learning style, and uses them to develop reasonable goals with the member. The patient characteristics and goals are shared on an ongoing basis with the provider, some in the form of social worker-facilitated support groups. Interventions are then tailored to behavior change and the avoidance of disease-related complications. An important part of the model allows physicians to access an online registry of their patients. (*Healthcare Demand Management*, 1995).

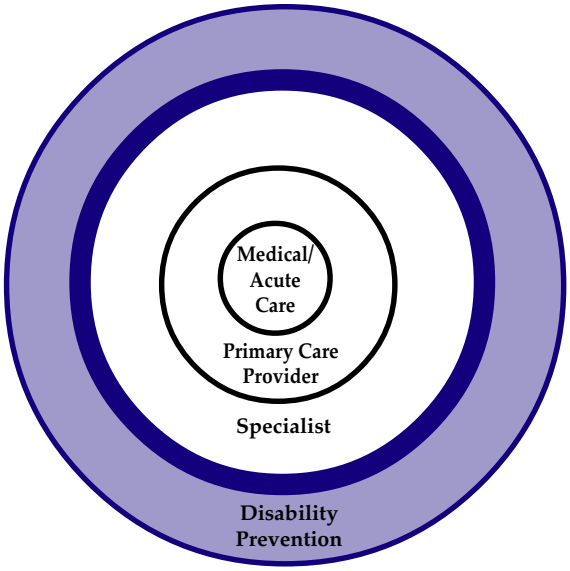
Humana Health Plan of Texas uses a nutritional health checklist as part of a overall health assessment that is conducted over the phone with all seniors by the Humana Health Education and Wellness Department. Once the assessments are complete, "frailty levels" on a scale of one to three are assigned to the seniors, (one indicates good health status, two indicates a visit to the physician for possible referral to a dietician, and three indicates an immediate referral to a physician). All assessments are placed in the medical record and sent to the primary care physicians for review. Nutrition interventions may include individual consultations with dietitians and disease management classes. The results of Humana's nutrition interventions have been quite positive. So far, 30 out of 200 diabetics have been taken off of insulin (Combs and Wellman, 1995).

Sutter/CHS in Sacramento has developed a risk identification tool that stratifies Medicare HMO enrollees into categories or levels of risk. Those with stable chronic diseases are identified as population groups and referred to disease-specific educational resources (e.g., diabetes, heart disease, arthritis). Those with predominantly social needs are triaged through social services to link individuals with needed interventions. Those with complex medical, social, and functional needs are assessed by an interdisciplinary team where client-specific plans of care can be created to meet needs, regardless of the setting. The data from the screening tool is also linked to the information system with the after-hours advice nurse. All patients identified at-risk are then followed until problem resolution or disenrollment.

Each of these programs demonstrates the basic principles of disability prevention in a chronically ill population: identifying needs or risk through a screening process, providing interventions that are directed at reducing or preventing the targeted disease or complication, and developing a case management or coordination process that follows the client through the system. In the ideal "managed" care network, disability prevention moves beyond a menu of add-on services and becomes the foundation on which the network delivers integrated chronic care.

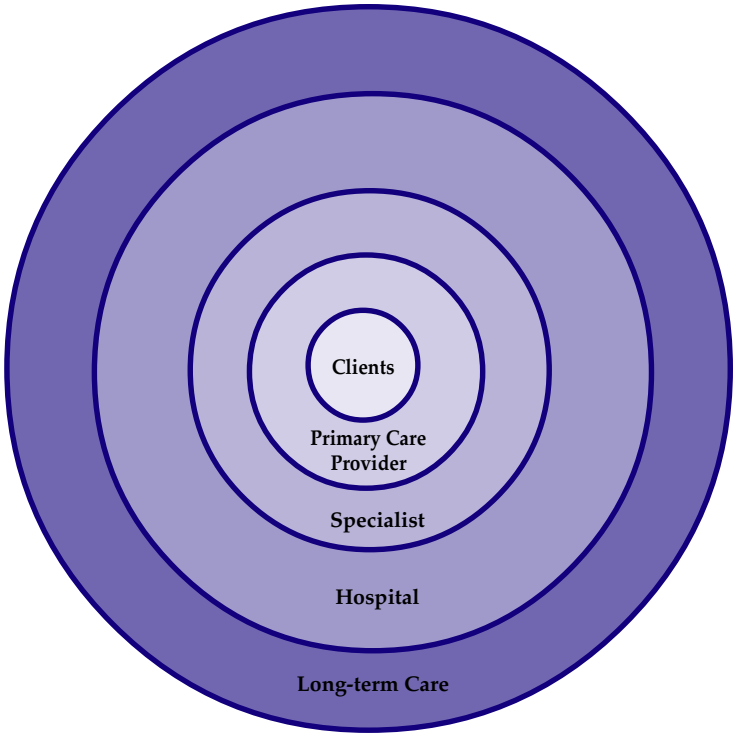
Figure 3: Models of Care and Disability Prvention

The medical model focuses on physicial/medical needs of individuals and emphasizes acute care. This places disability prevention on the "outer ring."



Disability prevention is practiced outside the acute care environment.

The CCN model for disability prevention emphasizes a holistic focus on client needs and supports primary care and the practice of prevention throughout the continuum.



Disability prevention is practiced at all levels of care

Adapted from Bruce Spiney, M.D., President, Northwestern Network
Source: Branch, Laurence G. "The Development of Health Promotion Guidelines and Recommendations." *Generations* vol. 18, no. 4 (Spring 1994): 24-27.

Conclusion

The traditional medical model around which our healthcare system has been established has kept disability prevention at the periphery (see Figure 3). Disability prevention efforts have mostly focused on primary prevention in the public health arena. The financing and organization of the delivery system has had perverse incentives built into it—whereby an increase in illness and disease results in increased payment to providers. Marketplace forces, practitioner values, consumer demand, and a recognition of the need to reform the system are moving disability prevention efforts to center stage.

The prevalence of functional limitation due to chronic conditions will increase over the coming years. It is well known that disability from a chronic disease or condition can often be prevented, or at least minimized, with appropriate measures—if disability prevention is pursued throughout life. Effective disability prevention involves interventions related to client education, support, proactive follow-up, and coordination of service. In the long term disability prevention can "pay for itself" through reduced costs to both clients and providers in a capitated system rather than through revenue generation.

References

Branch, Laurence G. "The Development of Health Promotion Guidelines and Recommendations" *Generations* 18, no. 1 (Spring 1994): 24-27.

"Caregivers Frustrated by Lack of Emotional Support." *Case Management Advisor* 7, no. 1 (Jan. 1996): 9-10.

Collins, J.G. "Prevalence of Selected Chronic Conditions, United States, 1986-1988." National Center for Health Statistics. Vital Health Statistic 10, no. 182 (1993).

Coombs, John and Nancy Wellman, "Nutrition and the Elderly." *HMO Magazine* 36, no. 6 (November/December 1995): 31-34.

Evans Lois,Yurkow, Johanna and Eugenia Siegler "The CARE Program: A Nurse-Managed Collaborative Outpatient Program to Improve Function of Frail Older People" *Journal of the American Geriatric Society* 43, no.11 (October, 1995); 1155-1160.

Folden, S. "Caring for Older Homebound Adults: A Chronic Illness Perspective." *Journal of Home Health Care Practice* 2, no. 1 (1989).

German, Pearl, "The Meaning of Prevention for Older People:Changing Common Perceptions," *Generations* 18, no.1(Spring 1994);28-32

Gerteis, Margaret, Edgman-Levitan, Susan, Daley, Jennifer and Thomas L. Delbanco, eds. "Through the Patient's Eyes." Jossey-Bass, San Francisco, 1993.

"Henry Ford Accomodates Capitation by Remodeling Case Management." *St. Anthony's Health Care Capitation Report* 2, no. 6 (October 1995): 5-6.

"HMO's Diabetes Program Tests New Model of Behavior Change," *Healthcare Demand Management*, 1, no. 4 (July 1995): 60-64

Institute of Medicine. *Disability in America: Toward a National Agenda for Prevention*. National Academy Press, 1991.

Lorig, Kate, "Self-Management of Chronic Illness: A Model for the Future." *Generations* 17, no. 3 (Fall 1993): 11-14.

Lumsdon, Kevin, "Disease Management: Hard Labor," *Hospitals and Health Networks* 69, no. 7 (April 1995): 34-42

Lumsdon, Kevin, "Working Smarter, Not Harder." *Hospitals and Health Networks* 69, no. 21 (November 5, 1995): 27-31.

Mockenhaupt, Robin, "Self-care for Older Adults: Taking Care and Taking Charge," *Generations*, 17, no. 3 (Fall 1993): 5-6

Mettler, Molly and Donald Kemper, "Self-Care and Older Adults: Making Healthcare Relevant," *Generations* 17, no. 3 (Fall 1993): 7-10

Pope Andrew M., Tarlov Alvin R., eds. *Disability in America*, National Academy Press, Washington D.C., 1991

Rakowski William, "The Definition and Measurement of Prevention, Preventive Healthcare and Health Promotion" *Generations*, 18, no. 1 (Spring 1994); 18-23

Scheitel S, et al. "Geriatrics Health Maintenance," *Mayo Clin Proc*, 71 (1996); 289-302.

Strauss, Anselm and Juliette M. Corbin, *Shaping a New Healthcare System*. Jossey-Bass, San Francisco, 1988

Van Norstrand, J.F., S.E. Funer, and R. Suzman, eds. "Health Data on Older Amercians: United States, 1992." National Center for Health Statistics. Vital Health Statistic 3, no. 27 (1993).

Vogt, Thomas M., "Cost-Effectiveness of Prevention Programs for Older People," *Generations* 18, no. 1 (Spring 1994); 63-68.

Yee, Barbara and Gayle Weaver "Ethnic Minorities and Health Promotion: Developing a Culturally Competent Agenda," *Generations*,

About the Author

Cheryl Phillips-Harris, M.D., C.M.D., is the Clinical Resources Director for the Sutter Health Center Region, Continuing Care Division. In this capacity she has developed a geriatric assessment program for frail elders enrolled in Sutter's Medicare HMO plans. She is Medical Director of five skilled nursing facilities, including Sutter's hospital-based subacute unit and an Alzheimer's special care facility. She is Medical Director for Sutter SeniorCare, one of 16 national PACE replication sites and Sutter VNA, a home health agency. Dr. Harris serves on the Board of Directors for the National Chronic Care Consortium and the American Medical Directors Association (AMDA), and she chairs the AMDA Education Committee. She completed her family practice residency and geriatric fellowship at the University of California, Davis where she currently holds a faculty appointment as Assistant Professor in the Department of Family Practice.

The National Chronic Care Consortium (NCCC) is a mission-driven organization of 27 leading-edge health networks dedicated to transforming the delivery of chronic care services. The NCCC's mission is to serve as an operational laboratory for enabling innovative health networks to establish prototype systems for better serving persons with chronic conditions.

Issue Brief: Perspectives in Disability Prevention Published June 1996, by the National Chronic Care Consortium.

Copyright © 1996 by the National Chronic Care Consortium. All rights reserved.

The John A. Hartford Foundation provides support for the development and publication of NCCC *Issue Briefs* and *Best Practices*.

Written by Cheryl Phillips-Harris, M.D. Edited by Deborah Paone and Anjali Russano,

For more information on the NCCC's complete vision of integrated chronic care across a continuum, please contact:

National Chronic Care Consortium
8100 26th Avenue South, Suite 120
Bloomington, MN 55425
Phone (612) 858-8999
Fax (612) 858-8982
CompuServe E-mail: 73654,3631