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WORKING PAPERS, INVITED RESPONSES, COMMENTS

Paper 2. Prevention of Disabilities Due to Chronic Conditions (about 56 pages)
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Summary

Chronic conditions are defined as diseases and syndromes of extended duration such as cardiovascular disease, cancer, chronic lung disease, diabetes, osteoporosis, osteoarthritis, hearing and vision impairment, and human immunodeficiency virus (HIV). Almost half of all working-age people have one or more chronic condition, with the percentage increasing among the elderly to about 80 percent. Disability is the ultimate consequence of living with chronic health conditions that are not treated and managed in a timely way with appropriate services.

1. Additional epidemiological, biomedical and evaluative research is needed in the areas of:
   - Surveillance to collect more accurate data on functional limitations and disabilities due to chronic conditions. Increased emphasis should be placed on collecting data on underserved groups (e.g., minorities, rural populations, the elderly, and women).
   - Biomedical research on secondary conditions resulting from the functional limitations associated with disabilities.
   - Research to develop new and more effective adaptive devices.
   - Evaluations to determine the effectiveness of available medical, rehabilitation, and psychosocial prevention strategies.

2. Access to preventive services should be enhanced by:
   - Improving the physical access to prevention and treatment services through improved transportation services and architectural and structural design.
   - Improving coverage and complexity of reimbursement and payment mechanisms.

3. Availability of services should be improved by:
   - Increasing the quantity of existing services, appropriate utilization of trained professionals, and availability of adaptive devices.
   - Enhancing availability of existing innovative services by mobilizing community resources and support groups (e.g., religious and fraternal organizations, civic associations, schools, community-based groups).
   - Increasing the availability of sensitive and appropriate home health services.

3. Efforts are needed in the area of professional education and training to:
   - Increase general recruitment efforts at appropriate schools of allied health professions, with special efforts to target underserved populations.
   - Include instruction on the relationship of chronic conditions and disability in undergraduate, graduate, and continuing education curriculum for physicians and nurses.
   - Expand educational and information efforts for employers, and encourage them to make needed modifications to utilize fully the talents of their employees with disabilities due to chronic conditions.

5. Patient, family and public education should be strengthened to:
   - Increase the level of health education being provided at the national and local levels through the media, schools, voluntary agencies, etc…
   - Improve the level and quality of health education being provided by nurses, physicians, and other health professionals to individuals with disabilities due to chronic conditions and their families.

6. Coordination of services should be improved by:
   - Designating a federal group at the national level to oversee implementation of a national plan and to increase coordination among federal agencies.
   - Establishing community-based interdisciplinary groups at state and local levels to plan coordinated programs for prevention.
   - Increasing participation of minorities in the development of community-based services.

7. Continued advocacy efforts are needed in the following areas:
   - Community-based advocacy programs to help guide individuals through the complex health care and social service systems, and to advocate for needed changes in those systems.
   - Buddy systems where individuals with similar disabilities are paired to provide support and advocacy for one another.
   - Coordinated efforts to advocate for reforms in societal norms and perceptions of people with disabilities.

I. Background

Chronic conditions are defined as diseases and syndromes of extended duration. Once an individual is afflicted with a chronic condition, that condition may affect him or her for the remainder of life. Almost half of all working-age people have one or more chronic conditions (Krute and Burdette, 1980). This percentage increases among the elderly to about 80 percent (Guralnik et al., 1989).

This Working Paper focuses on the prevention of disability due to chronic conditions with onset during adult years only. Strategies are needed, particularly for individuals who are under 50 years of age, to reduce the disease and cost burden of disability due to chronic conditions. This burden is described below for several major chronic conditions.

Cardiovascular Disease: Almost 67 million Americans currently have one or more forms of cardiovascular disease. Coronary artery disease alone affects about 7 million Americans, causes over 500,000 deaths annually, and costs the nation approximately $43 billion dollars per year in direct and indirect costs. Stroke is also a major cause of mortality and morbidity, with almost 150,000 people dying of strokes and another 400,000 to 500,000 suffering nonfatal strokes each year. One of the major modifiable risk factors for

cardiovascular disease is high blood pressure, which affects approximately 30 percent of adults. The prevalence of high blood pressure prevalence increases with age, ranging from a low of 2 percent for white females aged 18 through 24, to 83 percent for black females aged *65* through 74. Overall, blacks have a higher prevalence of high blood pressure than whites (38 percent versus 29 percent) (PHS, 1990). Another key risk factor is serum cholesterol levels; an estimated 99.8 million Americans have levels that increase their risk of heart disease (AHA, 1989).

Cancer: Cancer accounts for 20 percent of the deaths in the U.S., 11 percent of the total cost of disease, and 18 percent of the total cost of premature death. Trends from 1973 to 1985 indicate that the age-adjusted incidence rate for all cancer sites combined has increased, with a more rapid increase for blacks than whites and a greater increase for men than women. About 75 million, or one in three Americans now living, will eventually have cancer (PHS, 1990).

Chronic Obstructive Pulmonary Disease: Nearly 80,000 people die each year due to this condition, with cigarette smoking accounting for 82 percent of these deaths. But death occurs only after an extended period of disability and many individuals with chronic lung disease die from other causes. In 1988, nearly 13 million people reported having chronic

Bronchitis or emphysema: In 1979-81, chronic bronchitis and emphysema caused 169 million days of restricted activity per year, or nearly 2 months of restricted activity a year for each affected person. In 1983-85, chronic bronchitis and emphysema accounted for 2.4 percent of all activity limitation due to chronic conditions (PHS, 1990).

Diabetes: Approximately 7 million people in the U.S. have been diagnosed with diabetes, and it is estimated that a similar number would meet the criteria but have not yet been diagnosed (CDC, 1990a). Diabetes is an underlying cause of 37,000 deaths annually and a contributory causes of another 113,000 deaths (CDC, 1990b). It is associated annually with 390,000 hospitalizations for ischemic heart disease and 128,000 for stroke, 56,000 lower extremity amputations, and 11,000 new cases of end-stage renal disease. Diabetes is also a major cause of blindness. Estimated direct and indirect costs associated with diabetes are over $20 billion (Center for Economic Studies in Medicine, 1988).

Osteoporosis: Osteoporosis is a menopause- and age-related condition characterized by decreased bone mass leading to increased skeletal fragility and fracturing. It affects about 24 million Americans, including 50 percent of women over age 45 and nearly 90 percent of women over age *75,* and is the major cause of approximately 1.3 million bone fractures each year. The total cost of osteoporosis and associated fractures, estimated to be between $7 and $10 billion in 1986, is expected to increase each year as the population ages (PHS, 1990).

During the 1980's, much progress was made in reducing mortality rates from chronic conditions. Changes in lifestyles and risk factor reduction were major contributors to this decline. The more than 40 percent drop in heart disease mortality since 1970 reflects dramatic increases in high blood pressure detection and control, a decline in cigarette smoking, and increasing awareness of the role of blood cholesterol and dietary fats. The comparable drop in stroke death rates - over 50 percent in the same period - also reflects gains in hypertension control and declines in smoking (PHS, 1990). Yet, the prevalence of chronic conditions continues to increase.

TABLE 1 shown next, indicates the most recent data on the prevalence of chronic conditions for the U.S.

civilian non-institutionalized population, all ages. (See Section II, Prevention Strategies, for a discussion of strategies to improve the reliability and validity of data such as these.)

Chronic Condition	Number (in thousands)	Rate (per 1,000 people)
Chronic Sinusitis	33,658	140
Arthritis	31,292	130
High blood pressure	29,257	122
Deformity or orthopedic impairment	26,878	112
Hay fever or allergic rhinitis without asthma	22,413	93
Hearing impairment	21,864	91
Heart disease	20,258	84
Chronic bronchitis	11,894	49
Hemorrhoids	11,031	46
Asthma	9,934	41
Migraine headache	9,222	38
Dermatitis	9,025	38
Visual impairment	8,365	35
Varicose veins of lower extremities	7,632	32
Tinnitus	6,361	26
Diabetes	6,221	26
Cataracts	6,105	25

(Source: National Center for Health Statistics, 1989.)

Risk of Disability Due to Chronic Conditions

Disability is the ultimate consequence of living with chronic health conditions that are not adequately addressed. Such disability occurs in a number of arenas; however, the only one for which reliable data exists is activity limitation, since it is most easily measured.

TABLE 2 shown next, indicates that a significant amount of activity limitation due to chronic conditions exists among people of all ages.

Chronic Condition	Number (in thousands)	Percent Distribution
All conditions	32,540	100.0
Orthopedic impairments	5,220	16.0
Arthritis	4,000	12.3
Heart disease	3,736	11.5
Visual impairment	1,438	4.4
Intervertebral disk disorders	1,424	4.4
Asthma	1,411	4.3
Nervous disorders	1,289	4.0
Mental disorders	1,284	3.9
Hypertension	1,239	3.8
Mental retardation	947	2.9
Diabetes	885	2.7

Hearing impairments	813	2.5
Emphysema	649	2.0
Cerebrovascular disease	610	1.9
Osteomyelitis/bone disorders	360	1.1

(Source: National Health Interview Survey, 1983-85)

Grouping related causes, the primary causes of activity limitations due to chronic conditions are mobility limitations (38 percent), chronic diseases (27 percent), sensory limitations (8 percent), intellectual limitations (7 percent), and other causes (20 percent).

By far, the group most affected by disability due to chronic conditions are the elderly. Among people aged 65 and older, 80 percent have one or more chronic conditions, and 20 percent are limited in their capacity for self-care or activities of daily living, such as housekeeping or shopping. In addition, the severity of limitations increases with age. Overall, the risk of chronic conditions causing work limitation is 2.6 times higher at ages 45-69 than at ages 18-44. Similarly, the risk of becoming unable to work is 4.3 times higher and the risk of needing assistance with basic life activities is 3.3 times higher at ages 45-69 compared to the younger age group.

In general, women are more likely to be limited in activity than men by disability due to chronic conditions (14.5 percent compared to 13.6 percent, respectively) (LaPlante, 1988). This discrepancy is also true of minority populations (see later discussion).

People with disabilities due to chronic conditions are high consumers of medical care resources. The use of these services also increases with age. The elderly with chronic activity limitations had 8.7 visits to physicians per year, as opposed to 4.3 visits for people with no activity limitations. The elderly also had 41.2 hospitalizations per 100 individuals, compared with 14.8 for those with no limitations in activity. The 46 percent of elderly people who were limited in activity because of chronic conditions accounted for 63 percent of physician contacts, 71 percent of hospitalizations, and 82 percent of all the days that older people spent in bed because of health conditions (NCHS, 1981).

Comparable data on the impact of disabilities on middle-aged individuals (e.g., aged 40-60) do not exist.

Race/Ethnicity and Disability. Asian Americans/Pacific Islanders, black Americans, Hispanic Americans, Native Americans, and Appalachians in the U.S., in addition to other underserved groups, are often in double jeopardy when faced with disability due to a chronic condition. These groups must deal with the same struggle for independence that all Americans with disabilities face; however, their racial/ethnic origin often complicates their ability to obtain equitable services and care. Disabilities are further exacerbated by low literacy, high levels of under- and uninsured, lack of proper housing, and desperate economic conditions.

Although the prevalence rate of chronic conditions is higher among whites than nonwhites (487/1,000 compared with 466/1,000), the disability rate among nonwhites is much higher. For example, the rate of severe disability (i.e., being able to work or to work regularly) was 65/1,000 for whites and 108/1,000 for nonwhites. Nonwhites had twice the rate of hypertension than whites and a rate of severe disability 2.6 times that of whites (Krute and Burdette, 1980). Thus, for certain minority populations, when chronic conditions occur they are more likely to develop into disability. This could be due to the impairments being more

severe, as may happen when people do not receive timely care, or because of differing psychosocial environments.

Strategies to address disabilities due to chronic conditions must be developed in the context of and with respect for the culture and social circumstances of the targeted groups. Program design, development, and implementation must include the participation of individuals from each respective target group, to assure linguistic and cultural relevance. The cultural and social practices of minority groups should be viewed as positive attributes in carrying out programs and providing services, not as factors that impede the process.

Secondary Conditions. This paper is concerned with the prevention of disability in those with chronic conditions, as well as the prevention of secondary conditions. These conditions can either be:

Conditions that are causally related to a primary disabling condition (e.g., chronic condition and/or injury), or that are produced by the treatment of that primary condition; or Concomitant conditions that are not necessarily related to the primary disabling condition, but exacerbate that primary condition and its treatment. These can be both acute and chronic in nature.

The body is homeostatic with finely tuned and interconnected mechanisms. A permanent loss to one or more systems, even if properly managed, can cause extraordinary stress on other vital systems. Consequently, as individuals with chronic conditions begin to experience functional limitations and disabilities, they also may begin to suffer from secondary conditions which can incite other impairments and dysfunctions. This process yields “insidious” cycles which reduce the capacity of the individual’s entire system. For example, an individual with uncorrected scoliosis (or other neuromuscular dysfunction) may later in life begin to develop respiratory disorders because of pulmonary dysfunction. This “shortness of breath” causes the individual to limit his or her activities which in turn, negatively affects motor neuron and muscle control. As the individual ages, cardiovascular and other respiratory disorders (such as pneumonia) may also develop.

In addition, individuals with chronic conditions often are susceptible to major infections. Furthermore, the medical consequences of the same level of acute infection tend to be more serious in someone with a chronic condition than in anyone without that condition. For example, someone with multiple sclerosis may develop frequent urinary tract infections. In an individual with severe to moderate disability, the fever associated with the infection may lead to weakness, difficulty in swallowing, and decreased mobility. These symptoms in turn may result in decubitus ulcers, pneumonia and dehydration, all of which are preventable conditions if recognized and treated early.

These secondary conditions occur because of increased risk of inadequate knowledge, monitoring tools, and access to appropriate health care. The health care system is not yet fully equipped to manage the range of disabilities and secondary conditions that often accompany chronic disorders. As outlined in the Introduction, the disabling process is not a unidirectional one. Impairments can be either fixed or dynamic; functional abilities can be restored as well as lost. Interventions exist that can prevent progression of the process or even reverse that process. In addition, proper treatment of one chronic condition or disability will often positively affect others, supporting the need for a holistic approach to treatment through proper case management.

Major themes. Several themes pervade throughout any discussion of disabilities due to chronic conditions. These themes are described below, and set the stage for the strategies presented in the following section of this report.

Importance of Preventing Pathology. Extensive clinical and epidemiologic studies have identified effective strategies for preventing many major chronic conditions. For example, an individual's risk of cardiovascular disease is significantly reduced when he quits smoking, controls his blood pressure, lowers his serum cholesterol level, maintains ideal body weight, exercises regularly, and minimizes excessive stress. Similarly, lung cancer can be prevented by avoiding or quitting smoking; and skin cancer can be prevented by using sunscreens and reducing direct exposure to the sun's ultraviolet rays. Other chronic conditions, like diabetes and breast cancer, can be detected at early stages through appropriate screening tests and treated before functional limitations and secondary conditions occur.

Prevention of pathology is usually more cost-effective than addressing the consequences of the pathology at later stages. Personal and environmental controls (e.g., engineering designs to reduce exposure to occupational dust) often cost less in the long run than the total cost of treating the resulting pathology (e.g., for chronic obstructive pulmonary disease) and in compensating for days of work lost. In addition, the variety and complexity of strategies needed to address a chronic condition increases significantly as that condition worsens and additional impairments and functional limitations arise. The cost of applying these multiple strategies also increases, particularly since they are often only addressed under crisis situations.

When prevention strategies are known, they should be applied as broadly as possible with an emphasis on preserving an individual's physical, mental, and spiritual well-being. Enhanced disease prevention efforts will serve to improve the quality of life for the nation's population.

Dynamics of Chronic Conditions. Due to the recent biomedical advances in drug therapy and surgery and to the increased lifespan, people may experience chronic conditions over a significant and increasing proportion of their lifetime. In addition, these conditions are gradually degenerative in nature, with a defined pathology that will run its course if left unchecked. At some point, the condition can begin to structure many aspects of the individual's life in terms of time, energy and emotions. For example, an individual with arthritis, or one who is undergoing chemotherapy for cancer, must deal continuously with the symptoms and disabilities caused by their respective chronic conditions.

Chronic conditions often occur simultaneously. This has become increasingly common with increases in life expectancy and the ability of medical technology to avert death without always restoring health. For example, it is quite common for an elderly individual to suffer from arthritis, vision and hearing impairment, and high blood pressure. The prevalence of multiple chronic conditions (or co-morbidity) is also the result of the decreased resiliency of an individual with one chronic condition, which weakens the body's systems. This multiplicity of conditions complicates the clinical picture and makes treatment of any one of the conditions more complex. Much remains to be learned about how to manage individuals with multiple conditions.

Chronic Conditions and Dependency. Society's expectations of individuals with chronic conditions may be different from those of individuals with acute conditions. The latter group of individuals are temporarily excused from their normal daily responsibilities of work, family and home, with the expectation that they will soon recover to resume them. On the other hand, individuals with adult onset chronic conditions may be permanently excused by society from daily "adult" responsibilities, transferring them into a dependent, "child-like" role. This externally imposed perception has a profound effect on the individual's self-image and self-esteem.

It also affects the lives of family members and close friends for the duration of the illness. For example, the husband of a woman with breast cancer might be faced with a readjustment in the previous distribution of household chores (e.g., he must now sweep the floors and clean bathtubs), as well as having to deal with feelings of helplessness and fear of the losing his spouse.

Dependence due to chronic conditions also increases the need for support in performing personal care or home management activities. Individuals who serve as caregivers, either professionally or as volunteers, are called upon to perform an increasingly wide array of services - from assistance with the activities of daily living such as bathing, eating, and dressing, to household chores such as shopping, banking, and cleaning. Performing these activities for oneself, as well as on behalf of someone else, puts these caretakers at great risk of stress, "burnout," and resentment of the person with a disabling condition.

Importance of Independent Living and Quality of Life. The goal of disability prevention is to support independence, productivity, and integration among people with chronic conditions. Individuals should be able to remain in their own homes and communities so they can continue to participate in those communities to the fullest extent possible. This sense of "community" and the ability to remain in one's own dwelling place, are two essential ingredients of a high quality of life. Institutionalization (e.g., in long-term care facilities) is a consequence of the failure to prevent disability in the individual with chronic conditions. It erodes self-esteem and is a most feared outcome for adults. Homemaker services for assistance with meals, shopping and bathing; attendant care for support with daily living and employment activities; simple aids and equipment for kitchen use; and structural adaptations to accommodate wheelchairs are but four strategies that should be fully explored to support independent living.

Prevention as a Shared Responsibility. Chronic conditions have biomedical causes (i.e., pathologies and impairments) which can be addressed by the medical care system. However, many people with chronic conditions regularly visit a specialist for treatment of their primary condition. This specialist tends to address the specific needs for which he or she was trained, and often does not provide the same level of expertise and attention to the diagnostic and therapeutic services for secondary conditions. A broader, more holistic, approach is needed in the care of chronic conditions to identify more consistently additional medical needs and to make proper referrals.

In addition, as chronic conditions progress (i.e., as functional limitations and disabilities occur), their manifestations become more complex and may involve marital discord, loss of employment, lack of adequate insurance to cover visiting nurses, etc. To address these needs effectively, the health care system must broaden its role to assume responsibility for identifying all needed medical <u>and community</u> resources, and for making appropriate referrals. These community resources include self-help groups, religious organizations, independent living centers, community-based groups that represent cultural and ethnic groups, and schools.

Strategies for prevention should view the individual as a total person. The tragedy of AIDS has taught an invaluable lesson in case management. Concomitant problems must be managed as a whole since the failure of one bodily system will have an impact on other systems. Models are needed that include the medical system but are not wholly dependent on it. These models should encompass the medical, rehabilitation, and psychosocial models of health care, for only with the full integration of all major health sectors of society can disability due to chronic conditions be prevented effectively.

II. Prevention strategies

Featured in the appendices of this proceedings, is a list of interventions that are based on numerous research studies has been compiled. Effectively applied, those interventions may prevent much of the disability due to the major chronic conditions. Call the CDC, Disability and Team for the appendices to these proceedings.

Tables in the appendices demonstrate that, as a result of one (sometimes very specific) pathology, an individual can experience a broad range of functional limitations and disabilities.
However, application of the interventions listed can, in many but not all cases, prevent an individual with a chronic condition from becoming progressively dysfunctional or reverse the disabling process for an individual who is already experiencing functional limitations.

The appendix tables also show the major secondary conditions that can result from the primary chronic condition and its related disabilities. Listing these secondary conditions reinforces the earlier description of the interrelationship between primary and secondary conditions.

As is apparent from the prevalence of disabilities, not all Americans benefit fully from the known interventions which can help to prevent disabilities.

The major gaps in prevention and suggested strategies for addressing each gap are presented in this section in the following categories:

1) Research (epidemiologic, biological and evaluative)
2) Access to quality services
3) Availability of services
4) Professional education and training
5) Patient, family, and public education
6) Coordination of services
7) Advocacy

Although this Working Paper recognizes that prevention of pathology of chronic conditions is of utmost importance, it emphasizes prevention of functional limitations and disability because they are relatively neglected in current research and service delivery efforts. This emphasis is also needed in light of the millions of Americans who currently experience the clinical manifestations of chronic conditions and resulting disability.

It should be noted that these strategies assume continuation of the present composition and structure of the nation's health care system. The prevalence of disability cannot be minimized, however, without fundamental reform in that system. Tackling this issue was considered to be beyond the scope and the time limitations of this Working Group but should be considered fully at the national level by a similar multidisciplinary group.

1) Research: epidemiologic, biomedical and evaluative

GAP 1: Inadequate epidemiological data on populations with disabilities due to chronic conditions.
Although much demographic and epidemiologic data exist on disability due to chronic conditions, more data is needed to assess the health and social burden of disabilities due to chronic conditions, analyze trends,

and evaluate program impact. Although disability statistics are produced by many sources, these sources do not individually or collectively provide national statistics with a consistently applied, widely accepted definition of disability. Information on the prevalence of disabling conditions exists but not on the underlying risk factors. In addition, no comprehensive data exist on the numbers and types of functional limitations and disabilities due to chronic conditions, including data on specific populations (e.g., women, minorities, elderly) which can be used to identify target groups that are at increased risk of developing disability due to chronic conditions. Similar data on secondary conditions are also not available.

STRATEGIES:

• Expand existing surveillance systems to collect more accurate data on underserved groups (e.g., minorities, rural populations, the elderly, women, etc.). Existing data often aggregates all racial/ethnic populations in the U.S., or focuses on one racial/ethnic group. These generalizations not only provide a distorted view of the true epidemiological perspective of chronic conditions, but also ignore the diversity and richness of each minority group. The lack of data on the extent and nature of functional limitations and disabilities among each respective minority group is especially acute.

• Create new surveillance systems at the state and national levels to collect and analyze data on the numbers and types of functional limitations and disabilities experienced by those with specific chronic conditions. For example, current surveillance systems can estimate the number of arthritic patients in the U.S.; however, to prevent disability from arthritis, it would be more useful to know how many people with arthritis are unable to work or how many are in long-term care facilities. Or for people with multiple sclerosis, it would be valuable to know the percentage with speech impairments, vision impairments, or urinary incontinence. These data should be collected to facilitate analysis by programmatic eligibility requirements so that they can be used to plan targeted national, state, and community programs.

• Develop and implement tools for monitoring secondary conditions to identify the numbers affected, the types of conditions, etc. These tools should incorporate standardized codes for secondary conditions and could require insurance carriers to use these codes consistently so that billing and hospital abstract data will be more useful for epidemiological analysis. Access to billing data for research and analysis should also be improved.

• Expand epidemiologic research to identify additional risk factors for disability from specific chronic conditions (e.g., diabetes, most neurologic diseases). Much is known about the risk factors for developing some cardiovascular diseases but more research is needed about its related disabilities. Comparable information about many other chronic conditions and their resultant disabilities would also be extremely valuable. If the nation is to make major strides in improving quality of life, research to determine how to prevent major chronic conditions and disabilities must be supported. This research should identify risk factors in the psychosocial environment that may cause disability or diminished opportunities for people with chronic conditions and should utilize existing treatment centers to assure sufficient numbers of cases.

• Conduct demonstrations projects to identify the most effective methods for translating research results into operational interventions at the local level. The methodologies used in research projects are not always directly replicable in community-based settings but must be adapted to reflect existing social and environmental variables.

GAP 2: Inadequate biomedical research. Insufficient biomedical research has been done to identify the specific clinical relationships between primary chronic conditions and their related disabilities, and causally-

induced secondary conditions. The causes of these secondary conditions and key risk factors should be identified so that medical interventions can be developed and instituted.

STRATEGIES:

• Conduct biomedical research on secondary conditions resulting from the functional limitations associated with disabilities. Such research might determine, for example, the reasons why a person with peripheral neuropathy, from whatever cause, develops calcium deposits, osteoporosis, and kidney dysfunction. It could also produce more accurate procedures for measuring blood pressure or calcium absorption in mobility impaired individuals.

• Convene a group of experts to identify priority research activities for determining the impact of secondary chronic conditions on people with pre-existing disabilities. Since the number of research activities in this area is infinite, it is important for a well-respected national group (such as the National Council on Disability in conjunction with the National Institute on Disability and Rehabilitation Research) to prepare a list of the highest priority activities for use by federal and other research funding sources. This list should be distributed to all major research institutions to guide them in writing proposals.

• Require federal health agencies to prepare prevention impact statements on all funding requests for basic research. Just as Environmental Impact Statements are required for all major construction projects, statements that analyze the implications of basic research projects for preventive health care should also be mandated. This information would link preventive with curative medicine, and would provide valuable information for Congress or other funding sources.

• Increase the participation of minority populations in clinical trials and analyze findings to determine specific effects on minorities. The ability to identify risk factors and populations at greatest risk depends in large part on the inclusion of minorities in clinical trials. Minority participation seems to be sorely lacking at present due to inadequate efforts on the part of research institutions to reach out to members of these groups in an effective way. Steps should be taken to ensure that researchers include adequate representation of women and minorities in their studies, particularly research on the prevention of impairments that may lead to disability.

GAP 3: Expanded research on adaptive technology and self-monitoring tools

STRATEGIES: Continue to encourage research to develop new and more effective adaptive devices to prevent functional limitation and disability. Significant contributions have been made in the development of adaptive devices (e.g., prosthetic and orthotic devices) that have helped many people with disabilities maintain their independence and remain productive members of society. The design of these devices needs to be attractive as well as functional. They should also be available at reasonable costs. The use of social science data in engineering design of adaptive devices should be encouraged. Self-monitoring kits to measure inflammation, occult bleeding, and blood cell counts could also be developed. Lastly, research is needed to identify effective methods for teaching the proper use of these self-care tools and adaptive devices through community-based programs such as independent living centers.

GAP 4: Lack of data on the effectiveness of available medical, rehabilitation, and psychosocial prevention strategies

STRATEGIES:

• Identify outcome measures for current medical and rehabilitation strategies, and use them to evaluate the safety and efficacy of those strategies (e.g., speech-language and swallowing services for stroke victims, self-care). Insufficient data exist on the extent to which current prevention strategies (including those listed in the Attachment) are effective in preventing either impairment, functional limitations, or disability. These data would provide a basis for program planning at the national, state, and local levels, and could significantly influence resource allocation decisions.

• Evaluate selected psychosocial strategies to determine their cost-effectiveness in preventing individuals with functional limitations from becoming disabled, and distribute this information widely to relevant provider communities (e.g., specialists who treat people with disabling conditions). For example, the federal Independent Living Centers Program, funded by grants from the National Institute on Disability and Rehabilitation Research (NIDRR), supports 200 centers around the country to provide services on behalf of people with disabilities. This program should be evaluated to determine who is being served, what social support services they are receiving, and what results have been achieved. The feasibility of expanding the role of Independent Living Centers into health care delivery or support should be investigated.

• Evaluate models used effectively to manage one chronic condition to determine their applicability for other conditions. For example, the Twelve-Step Program, which has been effectively applied with substance abusers at relatively low cost, has been used recently with psychiatric disorders such as bulimia and anorexia. The success of this new application needs to be evaluated along with other similar endeavors.

• Analyze systems of care used by other countries to identify strategies that could potentially be effective in the United States. Switzerland, England, Sweden, and France (to name a few) have used some innovative approaches to improve the quality of life of people with disability due to chronic conditions. These approaches should be studied carefully to identify implications for the U.S., both in terms of structure and distribution of resources.

• Evaluate the extent to which age, gender, race, and cultural/ethnic origin affect access to services. Although some information is available on the differences in the use of services by various ethnic, racial, gender, and age groups, this information is by no means complete. Further analysis is needed to determine the reasons for disparities in access to services so that appropriate service delivery changes can be made.

• Conduct state surveys to identify the range of services being provided for people with disabilities. The results of such surveys should be distributed to all relevant service providers within each state, and should be used for both state and national planning efforts to identify gaps and improve coordination.

2) Access to services

The term “services” as used in this document is defined very broadly to include the full array of acute and long-term care services needed to address the medical, social and psychological needs of individuals with chronic conditions and related disability.

GAP 1: Physical access to services. Services for people with disability due to chronic conditions are often either geographically or structurally inaccessible. Among economically disadvantaged individuals, the expense of transportation and responsibility for child and elder care present significant environmental obstacles. These barriers need to be removed so that they do not prevent individuals from receiving the services to which they are entitled.

STRATEGIES:
• Improve the physical access to screening, treatment and prevention services through improved transportation services that are free from crime and not economically prohibitive.

• Improve the physical access to screening, treatment and prevention services through enhanced architectural and structural design. This could include ramps, wider hallways, elevators, etc.

• Promote institution-based or community-based provision of dependent care during attainment of screening, treatment, or preventive services.

GAP 2: Financial access to needed services. Many individuals at risk of disability due to chronic conditions do not have any insurance coverage while those who do may not have adequate coverage. Current insurance mechanisms may not reimburse for prevention services. Coverage may not be broad enough to encompass the range of specialty services needed by individuals with chronic conditions, disabilities, and secondary complications. In addition, insurance companies often require authorizations from "company" physicians for referrals and second opinions, resulting in significant delays in treatment and unnecessary worsening of health conditions.

STRATEGIES:
• Improve reimbursement and payment mechanisms for needed services. These mechanisms should include incentives to encourage compliance with treatment (e.g., monitoring of glycosylated hemoglobin values for people with diabetes), and should cover acute and long-term care services including physical therapy services such as recreation and rehabilitation services such as swimming. Payment schemes should also be broad enough to cover the full array of prevention and treatment services and should eliminate gaps in coverage when individuals change jobs or employers.

• Explore ways to decrease the amount of time physicians spend on paperwork for reimbursement of services (e.g., for Supplemental Security Income, taxi fares), since this takes time away from patient interaction. The amount of paperwork required for an individual who has both a chronic condition and a disability is greater than that for an individual who has only one or the other. This problem is compounded by the number of individuals who are required to carry more than one type of insurance to cover their health care costs. One possible strategy might be for physicians to be supported by the insurance carriers in their decision to delegate paperwork responsibilities to selected staff members (e.g., nurses).

• Explore ways to guarantee that the transition from welfare to employment does not penalize an individual with a disability due to a chronic condition by reducing his or her insurance coverage. Coverage by federal insurers (e.g., Medicaid, Supplemental Security Income) may at times be more complete than coverage by a private insurer. This situation should be corrected so that more complete coverage is provided by both.

• Examine the results of a study on access to health insurance currently being conducted by the National Council on Disability to identify the implications for health policy.

GAP 3: Access to culturally appropriate services

STRATEGY: Plan and deliver services that are culturally appropriate. Technical assistance should be provided to local communities, centers, clinics, civic groups, churches, etc., to develop plans for providing services that will be acceptable to, and therefore used more frequently by, the various cultural and ethnic

populations in greatest need. Staff from the community centers and clinics should collaborate with the local cultural and social groups to gather pertinent information about the motivation and behavior of the community, and design specific communication and service plans suited to that community.

3) Availability of services

GAP 1: Insufficient quantity of known effective services. Professional services and man-made adaptive devices exist to minimize or prevent functional limitation and disability. However, they are not always used to the fullest extent possible.

STRATEGIES:

• Increase appropriate utilization of registered dieticians, health educators, community health nurses, visiting nurses, and other ancillary health professionals by increasing referrals to them and assuring reimbursement for their services. The skills of allied health professionals are not adequately utilized to provide needed services to people with disabilities due to chronic conditions. Physicians should be encouraged to make appropriate referrals to increase their utilization, and health insurers should be encouraged to include reimbursement for their services in their standard insurance packages.

• Increase the availability of adaptive devices (e.g., oxygen, railings, ramps, computer technology, visual aids, protective shoes). As indicated on the tables in the Attachment, many adaptive devices currently exist to prevent functional limitation or disability. Insurance coverage for these devices should be instituted and health personnel should encourage their use whenever appropriate.

GAP 2: Lack of availability of existing innovative services. New and innovative social and psychological services to prevent disability due to chronic conditions are being created and tested on a regular basis, by both public and private agencies. Financial and personnel resources need to be enhanced so that these services are available to all in need.

STRATEGIES:

• Mobilize and increase access to community resources and social support groups such as:

Religious and fraternal organizations
Self-help groups (e.g., independent living movement)
Civic associations
Behavior modification services
Schools
Voluntary agencies
Outpatient clinics
Community-based groups that represent cultural and ethnic groups
Civil rights groups

• Increase the availability of adult and respite care services and services to support relatives and friends providing in-home care.

• Increase the availability of sensitive and appropriate home health services. These services should include (at a minimum) physical therapy, occupational therapy, speech-language and swallowing services, recreation therapy, nursing care, home health aids, personal care attendants, vocational rehabilitation, child

care, respite care, physician care, and architectural and environmental experts to improve the layout and structure of the home. These services would go a long way to assuring maintenance of independent living. Congregate housing opportunities should also be increased, especially for low income and minority populations who are less able to move in with their families.

4) Professional education and training

GAP 1: Sufficient numbers of trained professionals, particularly from underserved groups and in underserved areas. More health professionals, particularly those that provide ancillary medical services, are needed to better meet the needs of people with disability due to chronic conditions. In particular, there is a need for increased numbers of medical and allied health graduates who are members of underserved populations.

STRATEGY: Increase general recruitment efforts at appropriate schools of allied health professions. Such efforts should be targeted to underserved populations, since the percentage of black, Hispanic, Native American, and female professionals serving individuals with disability due to chronic conditions is far lower than the percentage of the population they serve who are members of those respective underserved groups. The acceptability of services is directly related to the level of comfort or trust that the client feels with those services. This comfort level increases if the services are delivered by an individual who truly understands the client's life experience and who is perceived to have the client's best interests at heart. Efforts should also be made to increase recruitment from rural underserved areas.

GAP 2: Adequate training of professionals. Current undergraduate and continuing education training do not adequately prepare professionals to prevent disability among individuals with chronic conditions. Effective intervention strategies and the major medical and psychosocial issues facing these individuals are not fully covered in current curriculum. For example, many in the medical profession still assume that, because chronic conditions are by nature progressive, there is no cause to be overly concerned when the vision of someone with multiple sclerosis is prematurely affected by steroids since that individual would eventually lose his sight anyway.

STRATEGIES: Include instruction on the relationship of chronic conditions and disability in undergraduate, graduate, and continuing education curriculum for physicians and nurses. Physicians in particular need to be educated about the concerns of people with disabling conditions and the treatments which prevent secondary conditions.

They also need communication skills to inform their patients of their risks and choices related to treatment. Additional education in the social and behavioral sciences is needed to understand more fully the relationship among social supports, impairment, and disability. Special attention should also be given to instruction in specific ethnic, cultural, gender, and age-related issues, especially in the clinical setting. Emphasis on prevention (e.g., when and for whom to make referrals for screening) should be increased.

• Investigate the feasibility of an expanded role for family practitioners in the management of people with disabilities due to chronic conditions.

• Increase the emphasis in health professionals' training on case management skills. Better cooperation among providers may lead to fewer cases of "burnout" among professionals and result in greater client satisfaction.

GAP 3: Adequate education of employers. Employers of people with disability due to chronic conditions need to be educated about the special needs of these individuals and the ways in which the work environment can be adapted to accommodate these needs. Many employers are beginning to recognize the value of these adaptations but much more work in this area is needed.

STRATEGY: Expand educational and informational efforts for employers to improve their awareness of the ways in which people with disabilities due to chronic conditions can function effectively in the work environment with appropriate management. Towards this end, the Centers for Disease Control should strengthen their relationship with the President's Committee on the Employment of People with Disabilities.

5) Patient, family, and public education

In this context, "family" is defined broadly to include relatives, spouses, close personal friends, guardians, and caretakers.

GAP 1: Appropriate quality and quantity of current public information about chronic conditions, disability, services and resources.

STRATEGY: Increase the level of health education being provided at the national, state and local levels through the media, schools, voluntary agencies, etc. For example, television, radio and newspapers could be used to publicize public figures who are willing to admit to having chronic conditions or to using adaptive devices: These individuals could serve as role models and could help to increase the acceptability and use of devices that prevent functional limitation (e.g., hearing aids). Role models should be selected to be effective with a wide variety of racial, ethnic, cultural, gender, and age groups.

In addition, voluntary agencies could establish national, state and local systems to make health professionals and people with disabilities more aware of available services and resources. These systems could include community-based resource specialists who would organize available information and inform doctors and patients of available services. They could also include an ongoing mechanism, possibly at the national level, for cataloguing and distributing available written material on the prevention and treatment of disabilities due to chronic conditions and for compiling resource directories of available services.

GAP 2: Improved quality and quantity of patient and family health education

STRATEGY: Improve the level and quality of health education provided by nurses, physicians, and other health professionals to individuals with disabilities due to chronic conditions and their families and caregivers. Development of standards of patient education can facilitate the communication of educational messages to individuals with chronic conditions. Education should be provided whenever these impaired individuals and their family members interact with the health care system (e.g., in clinics, emergency rooms, pharmacies).

6) Coordination of services

GAP 1: Lack of coordination at the national level. Activities for individuals with disabilities due to chronic conditions are supported by a variety of groups at the national level. These services need to be well-coordinated to ensure that limited resources are used as efficiently as possible.

STRATEGIES:
• Designate an interdisciplinary federal group to oversee implementation of a national plan.

• Support exploration by the National Council on Disability of a variety of ways in which to improve the coordination and effectiveness of federal programs affecting people with disabilities.

GAP 2: Lack of coordination at the state and local levels. There is also a lack of coordination among activities at the state and local levels. A multitude of services are provided by a wide variety of groups, but these groups are not always aware of each other or do not fully utilize each other's strengths.

STRATEGIES:
• Establish community-based interdisciplinary groups to coordinate programs for disability prevention. These groups should include representatives from the medical, rehabilitation and psychosocial fields and should be charged with identifying ways to integrate the rehabilitation and psychosocial fields at the community level.

• Increase participation of minorities in the development of community-based services. In addition, enhance the relationships between the religious community and other relevant groups to provide support for ongoing services. Any strategies to address disabilities due to chronic conditions must be grounded in an understanding and respect for the culture and social circumstances of the targeted groups. Program design, development, and implementation must include the participation of individuals from each respective target group, to assure linguistic and cultural appropriateness. The cultural and social practices of minority populations should be viewed as positive attributes in carrying out programs and providing services, not as factors that impede the process.

7) Advocacy

GAP 1: Sufficient social support for individuals with disabilities due to chronic conditions. Individuals with disabilities due to chronic conditions are often left to fend for themselves. They may find themselves faced with having to negotiate a complex medical care and social services system, which can be a difficult task even under the most favorable conditions.

STRATEGIES:
• Establish and strengthen community-based advocacy programs (e.g., independent living centers) to help guide individuals through the complex health care and social service systems, and to advocate for needed changes in those systems. These advocates should work with individuals with many types of disabilities so they can speak on behalf of greater numbers of individuals.

• Establish buddy systems where individuals with similar disabilities are paired to provide support and advocacy for one another. This is one effective type of support group and can greatly benefit individuals who choose to participate.

GAP 2: Coordinated "voice" for advocacy on behalf of individuals with disabilities due to chronic conditions. Individuals with disabilities due to chronic conditions also need advocates on a broader level to serve as an informed spokesperson on their behalf.

STRATEGY: Establish coordinated efforts to advocate for reforms in societal norms and perceptions of

people with disabilities (e.g., housing discrimination, employment, transportation, support for the blind). Much progress has already been made, as evidenced by the adoption of the Americans with Disabilities Act. But, as this report indicates, there is still much work to be done. Current efforts of the National Council on Disability, the primary agency for advocating changes in national policy, should be strengthened so that the gaps identified in this report can be addressed fully.

III. Implementation of strategies

Many of the barriers to the prevention of primary and secondary disabilities due to chronic conditions are implicit in the strategies listed in the previous section. The Working Group wished to highlight a few of those barriers to emphasize that they must be addressed if national prevention efforts are to be successful. These barriers should be viewed not as obstacles, but as opportunities for making great strides in the disability arena.

• A coordinated advocacy effort is essential for gaining national recognition of the current priority of disability prevention in policy development and resource decisions, and for raising that priority to be more consistent with the disease burden and societal costs.

• A strong public education effort is needed to improve society's perceptions of the elderly and of people with disabilities. Emphasis should be placed on continued acceptance of these individuals even when their expected (i.e., societally defined) roles cannot be fulfilled.

• The business and industry communities need to improve their acceptance of people with disabilities and their willingness to make necessary accommodations to improve the productivity of these individuals.

• Health professionals need to pay increased adequate attention to the range of health needs of those who have or are at risk of developing chronic conditions.

• The value of caregivers and personal assistants (e.g., attendants, readers, interpreters, and advocates) needs to be recognized and supported fully.

• Overall access to health care and psychosocial services needs to be improved, not only for people with disabilities but for all Americans. This access should include establishment of a coordinated system that allows all individuals with chronic conditions, regardless of their ability to pay, to receive prompt and appropriate treatment as well as preventive maintenance to avoid unnecessary secondary conditions and disabilities.

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INVITED RESPONSES TO THE WORKING PAPER ON THE PREVENTION OF DISABILITIES DUE TO ADULT CHRONIC CONDITIONS

A. Surveillance, Epidemiology, Data Needs and Sources

Daniel A. Goldman, M.D., M.P.H., Chronic Disease Epidemiologist, Texas Department of Health

I appreciate the opportunity to offer my reaction to the working paper on surveillance and epidemiology of disabilities due to chronic conditions. Overall, I think that both routine surveillance of disabilities (to monitor the health of populations) and special epidemiological studies (to determine the causes of diseases and disabilities) are important, and hope that the plan developed from the working paper results in better surveillance and epidemiology.

My understanding is that the working paper reflects highlights of a discussion rather than a comprehensive description. However, I found the report to be vague and short on specifics. It needs to be expanded with more detail and examples.

Gap on B-14: I agree with the concept that the epidemiological data are inadequate, but the explanation

seems vague. It would be helpful if the data sources and their strengths and weaknesses were listed. I am not sure that information on underlying risk factors does not exist. What about the National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (NHIS), Behavioral Risk Factor Survey (BRFS), and cardiovascular disease community intervention projects? Instead of stating that no comprehensive data exist on the numbers and types of functional limitations and disabilities due to chronic conditions, it would be more useful to list and comment on the data sets that are available.

Strategy #1 on B-15: I mostly agree that existing surveillance systems need to be expanded. I understand this strategy to mean that the sample size would be increased. Of course, one can always find a subpopulation small enough so that the results are unreliable.

Surveillance systems should be able to provide information on urban/rural differences, race/ethnic differences, and age differences. Special studies and surveys have tended to exclude women, but I am not aware that routine surveillance systems have done so. There is a definite problem in that almost every surveillance system does not define a Hispanic race group. However, although it is very popular to present statistics on racial differences in disease, it appears that different racial groups are very similar genetically, and that variations in disease rates can be mostly accounted for by differences in income, risk factors, and access to medical care.

Strategy #2 on B-15**:** Mostly agree. This is a worthwhile goal in theory but it would be helpful to have some indication of what kind of system would be used and how it might be implemented. Could the working paper give some examples?

Strategy #3 on B-15: Strongly agree. It is cost-effective to use existing systems for surveillance. Hospital data are already being used for billing purposes; why can't they be used more effectively for surveillance? Of course, many people with illness or disability do not go to a hospital, and changes in diagnosis and treatment can make it difficult to examine trends. Also, most hospital data systems do not collect a personal identifier such as Social Security Number, and therefore cannot account for multiple admissions for the same patient or link the data to mortality data or other data sets. To be useful, it is important that hospital discharge data sets include a personal identifier. Also, the data must be completely collected from a large enough area so that population-based rates can be calculated.

Strategy #4 on B-15: Mostly agree. This is a worthwhile goal, but I am uncertain if the methodology for measuring psychological and social risk factors is adequate for these research purposes.

Strategy #5 on B-15: Mostly agree. It is almost always true that research projects represent a best-case scenario, and the results are almost always more favorable than would be possible in a real-world situation. However, a demonstration project is also a type of research project.

Gap #2 on B-16: Mostly agree. Of course, more research would be useful, but I think that the clinical relationship between a chronic condition and the resulting disability is known in many cases, and is usually organ failure. Some of the major research questions that are not resolved are more basic and involve the causes of primary hypertension, atherosclerosis, insulin resistance, obesity, and cancer.

Strategy #1 on B-16: Agree.

Strategy #2 on B-16: Mostly agree. Although I doubt that the number of research activities is really infinite,

it would probably be helpful to have a group of experts prepare a list of high priority activities.

Strategy #3 on B-16: Mostly disagree. It is better to prevent disease than to treat established disease. However, disease prevention seems very different from environmental damage. Much research is not carried out to test a specific goal but simply to find out new things; unanticipated benefits can result. If a research project promotes disease prevention, it should be given a higher funding priority, but it seems to me that requiring a separate Prevention Impact Statement would be inappropriate since it would create more paperwork without a clear benefit.

Strategy #4 on B-16: Partially agree. Clinical trials limited to one study group are not necessarily invalid. There are basic biological differences between males and females, so it is almost always worthwhile to include females in research studies. However, the genetic differences between race groups seem to be very small compared to the variation within the groups. With a few exceptions (for example, sickle cell), race differences are largely due to socioeconomic factors or risk factor prevalence differences. These factors should be controlled for in a study. Results from studies involving only one race and sex group have been widely accepted, even though they were not for white males. Examples include studies of heart disease and coronary risk factors in Japanese who live in Japan and those who immigrate to the U.S., and studies of AIDS transmission in circumcised and uncircumcised blacks in Africa.

Gap #3 on B-17: Agree. I think this is a large need. Since these are devices that are sold to people, it might be appropriate to make some comments about the private sector.

Attachments: I think the idea of the tables in the attachment is good, but the implementation is confusing. There is too much information jumbled together. Also, the difference between a pathology and impairment seems artificial; the same applies to the difference between functional limitation and disability. It would help to be more specific about the manifestations and interventions.

The attachments should either be deleted or their format changed. A suggested alternate format:

<u>Visual Impairment from Type II Diabetes Mellitus</u>

Can Type II diabetes be prevented? Yes, with weight control, and possibly exercise and low-fat diet.

Can diabetes be detected early? Yes, with blood glucose screening.

Can early detection of diabetes prevent eye pathology (proliferative retinopathy or macular edema)? Yes, with weight control, insulin or oral hypoglycemic therapy, and blood pressure control.

Can eye pathology be detected early? Yes, with annual eye exams.

Can early detection of eye pathology prevent visual impairment? Yes. Laser surgery and vitrectomy can lessen visual impairment in many cases.

How is the patient affected by visual impairment? Any task requiring vision is difficult to carry out.

What can be done for the patient who has visual impairment? Specialized optical devices, vocational training, computer technology, mobility instruction, family support, adaptive skills counseling.

Douglas A. Fenderson, Ph.D., University of Minnesota
Dr. Verbrugge has discussed the model of disability used in the Institute of Medicine study, *Disability in America.* This model, as she explained it, depicts biological, environmental, and behavioral risk factors, in relation to life events interacting with a four stage disabling process. The interactions influence and are influenced by a construct called "quality of life." In that formulation, risk factors prior to the onset of pathology, and at each subsequent stage, are seen as the keys to preventing disabilities and associated secondary conditions. If that model is a reasonably valid way of looking at the disabling process, and Dr. Verbrugge has certainly been a cheerleader for that point of view, then an important agenda of risk factor analysis, the natural history of the so-called downward spiral of disability, normative data on sub-populations over time, and cost outcome studies, may be derived.

The history of public health as one of my former teachers, Dr. Gaylord Anderson, used to say is a "continuing redefinition of the unacceptable." Clearly public sentiment and policy leaders are saying that the incidence and quality of life consequences of chronic disease and other disabling conditions are no longer acceptable. Increasing prevalence of disabling conditions is a paradox of advances of biomedical science and clinical care. Thus, we note the heavy emphasis that the sponsors of this program have placed on the aspects of secondary conditions. The history of public health has been, in part, the history of the study of distribution of diseases in populations. But as the devastating epidemics of the past have given way to the present problems of chronic disease and disabilities, the old tools in epidemiology need to be adapted to new tasks. Thus we see the emergence of a branch of epidemiology known as "social epidemiology," and as indicated in the Institute of Medicine report *Disability Epidemiology.* These emerging variations on a venerable discipline are more than cosmetic. There are new theories, new bodies of knowledge in sociology and chronic disease that must be mastered if the cascade of risk factors is to be usefully understood.

As you know, there is a major national effort underway to look at the outcomes of medical care and a similar concept - standards of care criteria for specific conditions. The group at the Tufts New England Medical Center is under the direction of Dr. Alvin Tarlov, who spoke here yesterday morning and was also the director of the Institute of Medicine study. That group has published several important studies resulting from this programmatic effort. A key element in that work has been the formulation of a brief but robust outcomes assessment instrument, known as the SF36, developed by a former Rand scientist, Dr. John Ware.

This work, on patient populations by provider type and patient outcomes over time, is designed to answer questions about the relative advantage about proactive organization and service mix in relation to patient benefit. Many other groups in the country ale also- beginning to look at standards of care and outcomes measurements. These are complex efforts and, as complex as they may be, applying them to the disabling process, the subject of this chapter, is at least as challenging. If measurement of outcomes is an idea whose time has come, it will take a rigorous re-examination of practices and training in epidemiology to make the kind of progress envisioned here. I'd like to be more specific about that.

Progress in the new epidemiology will require a closer articulation with clinical medical care and other health care providers than has been customary for public health epidemiologists in the past. I am sure most of you have read the book, *The Future of Public Health,* a 1988 Institute of Medicine report. That report is not happy bedtime reading. The first chapter is entitled, "The Disarray of Public Health: A Threat to the

Health of the Public." Speaking of the relationship between public health and the medical community, the report notes "too often confrontation and suspicion are evident on both sides." But as is plainly evident, the study of disability prevention, and especially the risk factors for subsequent stages in the disabling process requires knowledge and data sources directly linked to clinical care and community service delivery sites. Thus we must rethink traditional public health surveillance strategies and relationships.

My final comments might be placed under the category, "perfection of means and confusion of ends." I sat in on several of the working group sessions as these papers were being prepared, as an observer. One of the things I observed was tension developing between the epidemiologists, the data purists, and those who view data as in the service of program. Each side had compelling arguments. The epidemiologists say, "If you don't have accurate data, how can you know what is to be done, what was of value and why?" On the other hand, the program types said, "We don't need incidence and prevalence data accurate to two more decimal places; we already know enough to get started with the improved programs of disability prevention." That tension is evident in this particular paper, which places heavy emphasis on science. In fact, under gaps, epidemiological, biomedical and evaluative research is the first category of gaps and strategies to be considered. Good science is basic to the resolution of these problems that are so costly in personal, societal and financial terms, but I would also recommend a re-reading of the report about the future of public health to keep these scientific needs in perspective in relation to the social and political environment which must support our efforts. Another major emphasis in the report, *The Future of Public Health,* was that many public health people are so convinced of the rightness of what they are doing that they don't believe that they need to engage the broader society in the justification and support, in the compelling arguments that are necessary to carry the day in the improvement, expansion and fulfillment of the public health mission.

As a member of the Institute of Medicine Committee that produced the *Disability in America* report, I can best summarize my views on the subjects we have here at hand by calling your attention to the Surveillance and Research sections of that report, which are summarized from the extensive deliberations on those subjects by the committee itself. Regarding surveillance the report says "Develop a conceptual framework and standard definitions of disability and related concepts as a basis for a national disability surveillance system. Such a system should be designed to characterize the nature, extent, and consequences of disability and antecedent conditions in the US population, to elucidate the causal pathways of specific types of disabilities, and to identify promising means of prevention and to monitor the progress of prevention efforts."

Regarding research, the report recommends "the development of a comprehensive national research program on disability prevention to emphasize longitudinal studies, focus on prevention and therapeutic interventions. Special attention should be directed to the causal mechanisms whereby socioeconomic and psychosocial disadvantage lead to disability. Training young scientists for careers in research on disability prevention should be a high priority." Thus, it is my view that the working paper that we are considering this afternoon advances the recommendations of the Institute of Medicine's study.

<u>Scott Campbell Brown, Ph.D., Center for Assessment and Demographics Studies, Gallaudet University Research Institute</u>

My comments will be a reaction as the notice was rather short. The area of chronic conditions is probably the most difficult of the three disability areas. **I served on the** childhood committee and, in a way, our task was relatively easy in comparison to the chronic one. In the case of childhood conditions, at least the age of

onset is well-defined at a fairly specific and early age. In the case of the injury group, they at least have a fairly well-defined cause. The chronic condition group is sort of left with everything else, including a wide variety of conditions and causes.

The chronic area includes diseases late in life, aging (to the extent that people believe that aging occurs), conditions that were genetic but have onset later in life as opposed to early in life, and cumulative insults which may be due to injury. As a result, there are many problems in looking at chronic conditions. The age of onset, the severity of the condition (which Dr. Verbrugge pointed out), and the fact that severity can change over time due to the insidious nature of the condition are all important. We're not discussing a static phenomena over a person's life. There may be interactions of causes of the various disability conditions that a person might undergo while aging. All this makes the area of chronic conditions a difficult one to examine and it makes surveillance and data analysis difficult.

When looking at children, we see that education data are used. There are a variety of surveillance data for children. When it comes to 65 and over, Medicare data will pick up a lot of information on our elderly. But the period between 18 and 64 forms a surveillance gap when it is very difficult to obtain comprehensive data on the disability conditions. There's also difficulty in monitoring what is a gradual process. Finally, the heterogeneity of the groups that comprise the populations to be examined and the conditions causing disablement also cause problems. Looked at from a surveillance point of view, I think the paper represents a rather good attempt to grapple with chronic conditions.

Important gaps are identified in the paper. The authors know the importance of defining the problem. They know the importance of studying risk factors, and there's some emphasis on secondary conditions. These are very important gaps that do need to be addressed in the area of epidemiological data.

In the area of biomedical data, they've done a service by pointing out the need for specific associations between chronic conditions and disabilities and secondary conditions. In this sense there may be a little bit of disagreement between myself and the second reactor. I believe that one of the strengths of the report is that it points out the need to take a holistic view of chronic conditions and the disabilities that result from them, as well as the secondary conditions. The emphasis on technology is an important one and, in the fourth area, the stress on available strategies is an important one too. The authors are talking about things that are available at this time and disseminating them and that represents a very constructive can-do approach.

The strategies to deal with the gaps are very relevant, and many of them are quite innovative. The urging of standardized codes for secondary conditions is a useful point that was also brought up in the injury surveillance meeting this morning. Translating research results into operational interventions at the local level must be done, despite the fact that it may be viewed as a research project. These ideas link back to the notion of taking what is available and making it meaningful to persons. with disabilities.

Finally, the idea of taking a look at particular conditions and seeing what is applicable to other conditions is very creative. Taking a look at what some of the other countries have done to intervene is also a useful approach. Both of these things are very creative ideas in order to make certain that we don't go around reinventing the wheel.

In general, this is a very good report. That said, I do feel that there are some problems with it. Many of the problems are perhaps not the fault of the group that was looking specifically at epidemiology and

surveillance, but may be due perhaps to the interactive process and the nature of a consensus report. These fall into kind of two areas.

The first area is definitional ambiguity. Though the report deplores it, definitional ambiguity is pretty rampant through the text and has a tendency to mar the results. In some sense, the chapter gives the disability phenomenon itself short shrift. This is perhaps due to the mandate of examining chronic conditions, but it seemed that the report grabbed onto the National Health Interview Survey (NHIS) for dear life. It allowed that survey to frame the analysis as opposed to specifically looking at what was needed. I'll give some specific examples. First, the paper begins with the definition of chronic conditions, then discusses cardiovascular disease, cancer, chronic obstructive pulmonary disease, and diabetes from the perspective of their impact on mortality as opposed to disability. Next, we see a list of prevalent chronic conditions that includes mental retardation and asthma, which are highly doubtful as adult-onset conditions as defined in the report. Now, as a member of the childhood committee, I'm not saying that you're poaching on my land but just trying to get across the point that, if you're pushing the *Disability in America* model, a document such as this does not make the best case for it.

We have confusion over whether the strategy is aimed at impairment or disability. Just as an example, the injury paper mentioned that approximately 2.6 million people have lower back pain. About one half of these people form the largest Workmen's Compensation beneficiary group and yet they are not particularly classifiable within a specific chronic condition. As another example, many people in the elderly ages have disabilities without an identifiable chronic impairment or condition. This causes a problem in analyzing the issue of secondary disability in terms of determining what the primary disability is and the primary condition.

Finally, in terms of defining the particular conditions, there's confusion over whether a secondary condition means secondary complication of disease or secondary disability. Just as an example, the attachment on hearing impairment does not list any secondary conditions. I'm very troubled by this statement and find it almost damaging. In fact, if you look at the works of Vernon and his colleagues at Oregon and other hearing impairment units, tinnitus is viewed in much of the research as being a secondary condition caused by hearing impairment. This is particularly true, if both result from a noise related injury.

I leave definitions now and move to my second main problem, which is that there tends to be a scattershot approach to some of the solutions. The sad part about this is that the strategies for some gaps can be easily expanded and broadened for all.

Let me close by talking about some of the strategies needed to be added to address these problems. The first is in the area of definitions. It seems to me there's one gap that is conspicuously absent here. We insist on science to determine our vaccinations and other preventative strategies, as well as to test our statistical analyses. Yet we find a willingness to take a particular model *(Disability in America)* and swallow it whole without scientifically testing it. In layman's terms, this just blows me away. The model may be adequate and useful, but we have heard over the course of the past two days several criticisms of it. A critical gap is the absence of testing of the model's validity and reliability to explain the disability phenomena. If we are going to understand the process and how it affects people's lives, we need studies, such as those conducted on Katz's ADLs, the Sickness Impact Profile, and the International Classification of Impairments, Disabilities and Handicaps. We need scientific testing of the *Disability in America* model and any other models which have been advanced in order to determine their efficacy.

Finally, in terms of broader solutions, let me give some examples of some things in the report which can be

broadened for all cases. The cross-cultural approach that's mentioned in intervention should also be broadened to analyze surveillance and epidemiological efforts of other countries. In many respects, the United States is in the dark ages in analyzing disability in comparison to the efforts going on in Europe, Australia and Canada. I refer you to Adele Furie's work for Statistics Canada; the work in Great Britain on Cross-Disabilities Scales; and the Netherlands Statistical Office's leadership in examining disability-free life expectancy. These are areas from which we can benefit without reinventing the wheel.

To that end, I commend you to at least an examination of the International Classification of Impairments, Disabilities and Handicaps. While I have many problems with the ICIDH, it is the first attempt to take a conceptual framework and at the same time add a taxonomy for classifying impairments, disabilities and disadvantage. There are many flaws with the taxonomy, but there is an international process available to criticize it and to take advantage of what is going on in other countries. We can then promote the effort to speak a common language, not only in the United States but worldwide, so that we can benefit from what is going on in other countries. At the same time, the knowledge of the United States can be employed to advance the condition of lives of people with disabilities around the world.

B. Access to Care, Quality and Coordination of Care, Financing

Milagros V. McGuire, District of Columbia Rehabilitation Services Administration

I am very pleased to be here at this conference which marks the beginning of a dialogue on the development of a national disabilities prevention plan. As stated at the onset of this conference, disability is the ultimate result of living with chronic health conditions not addressed in a timely manner with medical interventions and appropriate services.

Contrary to general assumption, the health status of a community is not primarily dependent on the health care system. Although heredity determines our basic constitution, and thereby our tendency toward health or disease, it is a given that the socioeconomic characteristics for any given group play a much more dominant role in determining its health status. Where we live, work, and play and what habits we keep are the real determinants of health status.

A group's health status is measured by morbidity and mortality, which in turn are measured in terms of causes of death by sex, age, or of occurrence. According to this chart which examines the health status of Hispanics, the nation's fastest growing minority group lacks access to health care. The United States' 20.5 million Hispanics encounter major barriers when trying to access health care and have higher rates of some diseases such as diabetes and AIDS.

A 1988 health survey by the National Center for Health Statistics shows that Hispanics tend to go to the doctor less often than non-Hispanic whites or blacks, mainly because they have neither health insurance nor the money to pay for medical care. Cultural factors such as difficulty speaking English, fear of the impersonality of the system, and lack of continuous care, tend to discourage Hispanics from seeking medical attention except in crisis situations. But even without proper medical care, Hispanics tend to live about as long as whites. While Hispanics get cancer less frequently, they are three-to-five times more likely than whites and blacks to develop adult-onset diabetes and to suffer complications from this disease. A 1986 study of 17 Texas border counties by the University of Texas found that uncontrolled diabetes among Hispanics led to numerous preventable complications. Of all the identified cases of diabetes-caused blindness, 60 percent could have been prevented with proper treatment, as could 51 percent of kidney

failures and 67 percent of diabetes-related amputations of feet and legs.

AIDS is also beginning to assume epidemic proportions. While Hispanics make up only 7.9 percent of the U.S. population, they account for 14 percent of the AIDS cases nationwide, including 21 percent of the cases among women and 22 percent among children.

Prevention Strategies
Prevention has two sides: one is the warding off of disease and the other is early detection which enhances the possibility of recovery and prevents complications or progressive loss of functional ability.

The growing trend in our health care system towards more sophisticated and costly modalities at the expense of primary care and prevention must be reversed. Acceptable and reasonable standards of health care must be established and made accessible to all of our population. The way health care is best delivered is in sufficiently small units so people can have personal care. Health care providers should be set up in teams which relate to a segment of a community, not just to people but to the agencies, the facilities, the schools, and other components of a "community." Replication of effective research projects should be adapted to reflect existing social and environmental variables at the local level. Community-based organizations such as the Independent Living Centers should be made the center of a coordinated, responsive health care system. However, safeguards or assurances must be put in place to require that the governing bodies (i.e., the boards of directors) of these private, community-based organizations are inclusive and representative of segments of the population they serve. Built-in assurances of the equitable apportionment of resources are essential to the efficacy of a community-based system.

We must evaluate the extent to which age, gender, race and cultural/ethnic origin affect access to services. We need a more responsive service delivery system. This means that personnel have to be able to communicate with the people they serve and be knowledgeable about the language and the customs of their "customers," so that effective, trusting relationships can be established. Respected members of the community and the support systems of the extended family should be used to facilitate access, availability and appropriateness of services.

Outreach efforts to increase minority populations' participation in clinical trials must be a requirement for the funding of any research or studies on the prevention of impairments.

Implementation of Strategies
The keys to effective health care and psychosocial services are acceptability and affordability. Acceptability comes from cultural sensitivity which builds trust. People must perceive in the system a genuine desire to meet their needs with their active participation and concurrence with the process. Affordability comes from more effective coordination and utilization of resources. At present a strong coordinated "voice for advocacy" has been established under the leadership of the National Council on Disability, with the collaboration of the Centers for Disease Control and the Minority Health Professions Foundation. This voice should be strengthened and expanded, possibly through networking with the Office of Minority Health, which funds disease prevention projects. Adequate financing of health care is indeed as essential as our commitment to the concept of health rights for all.

Mary Anne Farrell, M.D., Diabetes/Health Promotion Disease Prevention Consultant, Nashville Area Indian Health Service
Disclaimer: The views reflected in these comments do not reflect the official policy of the Indian Health

Service (IHS). They also do not reflect the viewpoint of any tribal group. They are my personal observations based upon 11 years of employment as a staff physician and consultant in the Indian Health Service.

Background Information Indian Health Service
The Indian Health Service provides preventive, curative, rehabilitative and environmental services to approximately 1.1 million American Indians and Alaska Natives. Eligibility for care is determined by tribal affiliation and geographic residence ("on or near" reservations). Approximately *55* percent of American Indians and Alaska Natives live off reservations and are not eligible for health care unless they return to reservations for care. The Indian population is younger than the United States population and has a lower socioeconomic status with 28.2 percent below poverty level compared to 12.4 percent of the total United States population. Age specific death rates are higher for all ages less than *55* years, due to higher mortality secondary to accidents, suicide, homicide, pneumonia, diabetes mellitus, chronic liver disease, and alcoholism. Disability data on American Indians and Alaska Natives have never been collected but most likely mirror causes of excess mortality. The younger age of death is reflected in the younger age of onset of disability due to injuries, diabetes, substance abuse, and interpersonal violence. Type II Diabetes is a particularly common cause of disability due to the young age of onset of disease producing tertiary complications around 40 or 50 years of age. In some tribes up to 50 percent of the adult population has this disease. IHS Outpatient Clinic data reveal the astounding statistic that otitis media and diabetes are the second and third most common reasons for clinic visits.

Overall Comments on Working Paper The paper is an excellent starting point for a national agenda on disability prevention; however, not enough emphasis is placed on the PRIMARY PREVENTION of the disabling disease itself. This is especially true with regards to cardiovascular disease, chronic lung disease secondary to smoking, Type II diabetes and human immunodeficiency virus. In addition, very little mention is made of chemical dependency and mental health issues as an adult chronic condition causing much disability. IHS graphs reflect the problems of suicide, homicide and alcoholism for American Indian people. These mental health areas should be addressed as a cause of disability in America. (Statistically, these problems are much more common than AIDS.)

Finally, the paper's tables with effective interventions for preventing disability due to chronic conditions by individual diseases are inconsistent, listing "none" as secondary complications in some cases and appropriately delineating many secondary complications for other diseases. These tables should be more carefully reworked.

General Indian Specific Comments Reference is made throughout the document to the development of culturally acceptable services at the community level by local teams. These, types of organizations are now being created in Indian country due to legislation which has enabled tribes to operate their own health care programs. They have been particularly successful in the field of health promotion and disease prevention. A circle is a common Native American symbol and a medicine wheel with its four quadrants of the physical, spiritual, mental and social embodies the elements for true health. For any disability prevention and treatment program to be successful in Indian country, it must acknowledge these four elements and give the th equal treatment. Twentieth century medicine concentrates primarily on the physical, with lip service to mental and social issues and total disregard for spiritual issues. Little mention is given to spirituality in this paper and perhaps it should be included as a powerful community resource for all people.

Comments by Prevention Strategies. In this section I will comment first on the national level and then

follow with pertinent examples for the Indian Health Service.

Research

In addition to creating accurate surveillance systems for disabilities for all U.S. populations, much more emphasis needs to be placed on research that targets primary prevention of common diseases such as coronary artery disease, Type II diabetes, chronic lung disease, and chemical dependency. Most research in America addresses TREATMENT of diseases and not PREVENTION of diseases. Community-based behaviorally oriented research must begin to be viewed as an area of legitimate scientific inquiry and funded as such. Special funds should be created for research in minority groups who bare the burden of higher morbidity and mortality rates. A recent funding effort by the National Institutes of Health (NIH) for diabetes and Native Americans attracted many applications by nationally recognized university-based scientists. In addition, the Indian Health Service in cooperation with tribal groups has been active in using both an Indian Specific Health Risk Appraisal and the CDC's Behavioral Risk Factor Survey to establish baseline epidemiology for many reservations. These studies need to be conducted on most reservations and expanded to other minority groups.

Access to Services

Access to rehabilitative services for Native Americans varies widely. It is dependent on geographic location (urban vs. rural), funding level of the service unit in which the patient resides, and use of alternate resources (e.g., private insurance, Medicare, Medicaid, Worker's Compensation, vocational rehabilitation). Transportation is a critical factor for many isolated tribes who must travel long distances to receive specialty care. Many of our patients do not have gas money or adequate vehicles. IHS and tribal groups will frequently have their Community Health Representatives assist with transportation, but this diverts their preventive services from the community. Most IHS sites are funded to a Level of Need (LNF) of only 50 - 70 percent. Therefore, preventive services and rehabilitation are also at a lower level of priority. If the patient does not have other resources, rehabilitative services frequently cannot be provided. Consideration should be given to creation of a nationwide system of rehabilitation care with single point access for all Americans, regardless of previous employment status and ability to pay.

Availability of Services

Like access, availability of services varies widely and is usually dependent on geographic location, with urban locations having a much wider range of services. Use of allied health professionals in a multidisciplinary "team" approach is crucial for prevention and treatment of disabilities. For many Indian communities this will mean working with local private and public health agency staff who are trained to become sensitive to the needs of the people they serve. A single point of access to this team needs to be created at the local level to provide continuity and consistency of care. This team should be able to stay abreast of the many changes which constantly occur in the field of rehabilitation due to the development of new technologies.

Professional Education

This is a crucial area to address for all people with disabilities in our nation. Our current health care system is predominantly oriented toward "chief complaint" acute medical care. Physician training needs to focus more on prevention of disease and maintenance of health rather than the treatment of existing disease. For example, most physicians have spent many training hours on the treatment of chronic lung diseases but never have received instruction in helping patients to quit smoking. Prevention training needs to be viewed as legitimate by universities and made a mandatory part of the curriculum. In addition, consideration should be given to the creation of national standards for the treatment of many chronic diseases. This was done in

diabetes by the Indian Health Service approximately four years before the American Diabetes Association adopted their criteria. Diabetes Program Quality Assurance Chart Audits are done using these standards and have been used to document an improvement in the quality of care. Consideration should be given to creating national standards of care for other common diseases such as coronary heart disease, chronic lung disease, osteoporosis, etc. We have found in the IHS that "what gets audited is what gets done."

Patient, Family and Public Education

This section is excellent. We are finding in the IHS that educating patients and their families to make them "activated consumers" is increasing the quality of our health care. For example, we try to teach patients the Diabetes Standards of Care so they can request ancillary services such as eye exams, cholesterol screening, etc. Another example of this strategy is seen in the national campaign for cholesterol. A cardiologist recently told me that since his patients are now asking about their cholesterol levels, his referrals to nutritionists has increased dramatically. Educated patients can change physician practice.

Coordination of Services

This area really needs to be broken down into three separate issues: primary prevention of disease, treatment of disease/prevention of disability, and treatment of disability.

1. Primary Disease Prevention

Historically, the real advances in public health in this nation have occurred due to improvements in sanitation and vaccination policies. Most infectious diseases are now controllable through antibiotics.

The diseases currently afflicting our nation are multifactorial in origin and are linked to socioeconomic status. Unfortunately, our national health care system remains focused on discovery and utilization of sophisticated technology and chemicals to treat existing illness. To impact the health of this nation, emphasis now needs to be placed on individual and community knowledge, attitude, and behavior. The Year 2000 Objectives for the nation are an excellent first step in the direction of prevention. The Indian Health Service has been active over the last ten years in developing programs for injury prevention, chemical dependency, dental prevention (fluoride and baby bottle tooth decay), maternal child health, and diabetes treatment and prevention. All successful programs have been largely due to local community effort and energy. The area of community based primary disease prevention is in need of research dollars to extract successful program elements and share successes to avoid "recreation of the wheel." IHS has begun health promotion/disease prevention Program funding, but the dollar amount is still very small. Funding should be created at a national level for high risk minority communities to create and evaluate primary disease prevention programs. Finally, attention needs to be focused on youth as a target group. Innovative school health education curriculums should focus on empowering students to make healthful lifestyle choices. True health education needs to become a national reality in our primary school settings.

2. Disease Treatment/Disability Prevention

In this area of interaction with the health care system, medical standards of care should be created by existing organizations (e.g., American Diabetes Association, American Heart Association, Cancer Society, American Lung Association). These standards could then be used by various third party insurers and accrediting organizations to assess quality of medical care. These standards should include both medical criteria and patient education. The American Diabetes Association's Diabetes Standards of Care are an excellent example of such an approach. The Indian Health Service Diabetes Program has been using this

approach over the last ten years. We have established multidisciplinary diabetes teams at most service units to provide continuing medical care and patient education for self-management.

Creation of a single point of access to a regional multidisciplinary team would solve many problems of the fragmented health care of complicated disability patients. Some successful examples of this approach in rural North Carolina include local pediatric cardiology clinics staffed by university physicians on a quarterly basis, and developmental disabilities clinics. Similar multidisciplinary clinics need to be created for adults, especially in the areas of spinal cord injuries, visual loss, AIDS, and neurological and orthopedic disabilities. It is impossible for the average family physician, internist, orthopedist, or neurologist to coordinate the many dimensions of these diseases. The IHS has developed a computer system (RPMS; case management) which is being utilized by some areas to track complex pediatric cases. Computerized case registers offer a means to track and coordinate patient care.

Advocacy

Here again, the single point access to a multidisciplinary community-based disability team should go a long way to create the necessary support for disabled individuals. It will also create a coordinated "voice" for the treatment and prevention of disability in America. Access for disability treatment should not be based on ability to pay or previous employment status. Attention should also be given to assuring that the viewpoint of all minority groups is incorporated into any national disability program.

Kris Manlove, Grady Memorial Hospital, Atlanta, Georgia

I would like to preface my reactions by stating that I have a real strong interest in the wellbeing of the elderly and other minority groups. Just looking at the statistics on chronic conditions stated in the paper, over 80 percent of our elderly have some type of chronic condition and over 46 percent of the elderly are limited in their activity because of chronic conditions. They actually account for 63 percent of the physicians' visits and 71 percent of the hospitalizations. This is staggering and yet it could be prevented. I find the situation very disturbing because I view the elderly as a fine wine. As they age they get better, given that they receive proper nourishment and care.

Chronic conditions and disabilities place a great demand on our health care system, as we all know. The working paper on disabilities due to chronic conditions identifies quite comprehensively many of the gaps in current prevention processes and mechanisms, and it offers valuable suggestions for filling these gaps.

On the other hand, the paper does have some shortcomings that I'll address throughout my reactions. As Dr. Farrell suggested, I think the paper is effective in the sense that it does attempt to address the holistic approach to prevention, offering strategies that affect the physical, mental and social well-being of an individual. The quality of care addressing each component is very important since the neglect of one could possibly negatively change the others.

We must change society's perceptions to accept individuals with chronic conditions as viable human beings worthy of an opportunity to life - as close to a normal human life as possible. When it comes to access to care, immediately one thinks of money and often unaffordable health services. Although this is true in many instances, access is also restricted by the lack of knowledge needed to provide the service, inability to meet the needs because of cultural barriers we have mentioned, and the lack of public awareness and education. This paper does do a good job of offering strategies to overcome these limitations; however,

despite the strong appeal in the paper to improve access to care and the obvious need for financing, coverage of financial alternatives is insufficient.

The insurance industry plays a very important role in deciding the fate of people with chronic conditions. It is very wrong that the very entity that exists to assist us in attaining health services is often the very system that denies us care that could possibly delay or prevent the onset of disabilities - with the later costing even more to treat if allowed to surface. There just seems to be no insurance with insurance; hence, we need to encourage stringent insurance reform strategies. It's not enough just to change reimbursement mechanisms; we need to change the entire system. Furthermore, where are the strategies to improve the economic status of those with chronic conditions? The time has come for new innovative approaches such as new funding programs for Medicare whereby we save and prepare for the future health care needs from the time of birth to the time of retirement.

In terms of research: research is invaluable in improving the quality of care available to prevent disabilities, especially since we currently have inadequate epidemiological information, inadequate biomedical research, and a lack of data on effectiveness of available preventive strategies.

The paper fails to emphasize that primary care needs to be a major focus area. As mentioned by Dr. Farrell, we need more affordable health care centers in every community -ones that are culturally adaptive and sensitive to their members' needs. On the other hand, we need to discourage the use of costly acute care hospitals while we place greater emphasis on public or county hospitals that predominantly serve the indigent population, allowing those without insurance the opportunity to receive preventive care. These types of hospitals can take the lead in coordinating community programs for the prevention of disabilities.

Grady Memorial Hospital right here in Atlanta is a prime example. If given the adequate resources to assist with capacity staffing and equipment, then a large number of uninsured could receive preventive treatment for chronic conditions. Being a teaching institution with a large minority population, studies can easily be done on prevention as it relates to these minority groups. In addition, the quality of care that our physicians provide is also vital to the prevention of disabilities. This paper indicates the need to educate our physicians during academic training about the value of preventing disability. The importance of allied health referrals needs to be stressed as well, as part of the team effort to promote weliness. Chronic conditions may not go away, but preventing disabilities can be just as rewarding and just as valuable as curing an illness.

Another way to improve the quality of professional care is to have the physicians themselves set the guidelines for medical care, since physicians are more apt to listen to each other. Then add quality assurance programs as another strategy to insure professional quality. Overall, the paper offers some key strategies for addressing prevention of disabilities; however, it's not just enough to identify the problems. We must impose and enforce mechanisms and regulations that will ensure that these strategies get carried out.

I would just like to note that Dr. Sullivan appears to be devoted to promoting healthy lifestyles. Let's just hope the words and ideas are turned into action soon.

<u>Lena Ricks, B.S.W., University of Michigan Hospital</u>
First of all, I want to say that I come to you as a person who has lived with a disability since I was seven. And I come to you with an independent living background, both personal and professional.

At a time when we are experiencing an ominous crisis in this country around health care costs, increasingly frightening discussions of rationing health care for people with disabilities, and more and more pandemonium in coordinating health care services for all, the news of this disability prevention program comes as a breath of fresh healthy air. I am a person with a chronic disability and an intellectual curiosity. I am aware and sensitive to media presentation of disability issues, especially health care. I must say the news has been dismal for far too long - Medicaid cuts, spiraling health costs, and rampant discrimination against persons with disabilities who have low incomes and need health care services. I fear that we are moving into a three tiered system of delivery of medical services, based on income. For example, first level of care, first class, for those who can afford it. Second level of care, "super saver," for those who have Medicare or Medicaid. And the third level, "marked for extinction," for those who have no health insurance.

The results of these socioeconomic decisions create a fear of abandonment and a sense of urgency for many people with disabilities. Many of my cohorts and I occasionally feel that we are "society's enemy," that we are in the middle of a Darwinian nightmare, and that only the fittest truly will survive. It would be far too easy to adopt a hopeless cynicism, and assume that as a member of either the "super saver" or the "marked for extinction" group, there's really no motivation to go on living. Therefore, there's no purpose in seeking out, or struggling for access to quality health care, or for maintaining a body that because of long-term disability is already unfit according to societal norms. However, like so many other childhood polio survivors, I've lived with polio for 40 plus years, and we don't give up easily. We're striving to remain healthy, be functionally able to live in the community, and continue contributing to society.

This disability prevention program addresses my hope for continued health care. I think other people with disabilities will feel the same way when new thinking about prevention becomes known. When we begin saying "prevention of disabilities, not prevention of people with disabilities," there will be an easing of anxieties in our community. When this happens we can begin thinking and acting in a health promoting mode, as opposed to the traditional sickness treatment mode which often implies an illness and deterioration focus.

As I read the working paper, it was clear to me that the experts who worked together to draft this document have not only a professional but also a personal commitment to the concept of prevention and to working on it. It is reality based, as reflected through their knowledge of the essential need for accessible public transportation, barrier free design, home health services that include personal care assistance, and the psychological need for acceptance by people with disabilities who want to live and contribute in their own community, not in a nursing home. These working papers are on target, and remarkably thorough and comprehensive. Any weaknesses or gaps had to be searched for; they were not glaring. But the concerns I do have are as follows:

1. More emphasis has to be put on mental health illness prevention. For example, some mental health consumers who are able to live in the community tell me that when they are feeling psychotic or experiencing suicidal ideation in their home, they may accidentally start a fire, create some other hazard to their health, and/or wander outside without thinking clearly. They could in fact wander into traffic and cause injury to themselves or others. They could hurt themselves or others unintentionally. A cost effective prevention method is to have a personal care assistant come into the home when the symptoms occur and act as a custodian temporarily, thus saving unnecessary hospitalization costs and reducing the risks of secondary disability from injury. This would also provide a sense of personal control for the consumer who could act as an employer. Clearly this idea needs to be better developed but it does provide an avenue of prevention for this population.

2. After reading the working papers, my conclusion is that the paper on Adult Chronic Disabilities reflects a narrow focus on chronic conditions. The paper is only specific to the prevention of disabilities due to chronic conditions with onset during adult years. I believe there is a need to include long-term disabilities from childhood and the incidence of activity conditions that progress and intensify with age. For instance, post-polio syndrome, juvenile arthritis, scoliosis, spina bifida, cerebral palsy, should be included in the category of chronic conditions to be addressed. Much can be learned and accomplished to prevent secondary conditions and new disabilities if we include them by expanding the list and the definition of chronic conditions.

3. The issue of aging with a chronic disability is important when thinking of preventing secondary conditions. This issue needs to be thoroughly developed. The implications are broad for preventive interventions for persons with activity limitations.

For my specific reactions to the paper, under access to services I would add a fourth gap to what is already written to address the lack of personal initiative and motivation on the part of persons with disabilities to seek out and access services. Persons with disabilities due to chronic conditions often lack self-confidence and have low self-esteem. This deficient self-respect leads to a sense of learned worthlessness or helplessness. They are left with the feeling that they don't deserve good quality care. It's a simple concept, but people who care about themselves take care of themselves. They eat properly, practice good personal hygiene, see their physicians when they need to, and exercise true health care. In addition, some people feel the traditional medical model of care leaves them feeling powerless, with little sense of responsibility or personal control in their own health maintenance. My strategy might be to create and promote shared responsibility between persons with disabilities and health professionals.

Health care professionals as well as health planners must become committed to sharing responsibility with consumers/patients in awe of the human spirit that naturally seeks growth and health. We could provide persons with disabilities with an individual "wellness plan," for example, a personal plan of "how to stay well, and when and how to access health services." We could encourage them to take and maintain self-control and personal responsibility for all areas of their lives, especially health care and prevention of secondary conditions. The sense of self-respect and control that accompanies taking an assertive role, with comprehension of the total situation, is critical for effective health maintenance.

The second section I would speak to is coordination of services. This section of the paper is clear and very concise; however, the problem of lack of coordination of services at federal, state and local level can't be overemphasized. Low income people, especially, and the general public are being victimized by the lack of a systemized approach to health care, "confusion of tongues," and agency efforts to perpetuate their own programs. The politics of greed and power to get their piece of the pie from an already stretched economy circumvents the very population they are mandated to serve. In a new world order I can visualize a strategy for improvement. We could establish a center for the prevention of bureaucracy in health care delivery systems. In all seriousness though, my true vision would be to see the agencies working together cooperatively to create the best health care system in the world - a system that reflects effective and ethical fiscal management.

In the third section, financing health care, financial barriers to health care are one of the chief reasons that low income persons do not access health care services when they are needed. We all know that. It accounts also for the high statistics of disabilities among minorities and other disadvantaged persons.

When you add the burden of primary disability to the financial burden, one can see why this group requires tremendous resourcefulness for successful existence. There are critical inequities in America's social welfare legislation. Many persons with disabilities have to struggle constantly just to survive.

While this social legislation reflects America's entrepreneurship, it also reflects a Darwinian philosophy of survival of the fittest, not what I envision in a country founded on the principles of equity and social justice for all. The current system of financing health care leaves many persons with disabilities vulnerable to bankruptcy from illness, accident and ongoing disability. Adequate health care coverage can assure early detection and intervention that can reduce or prevent risk factors for secondary disabilities. Most persons with severe disabilities depend on public health insurance for medical needs. They are often unable to access the health care services they need. Medicaid has an institutional bias and is oriented toward a medical model or sickness treatment model of care. Medicaid benefits often do not cover preventive or wellness care or ongoing maintenance services because they are patterned on the acute care orientation of private health insurance.

While I clearly respect the efforts for prevention of primary and secondary disability, I think it is folly to think of creating a national plan of this proportion without working in tandem with private and public health insurers. It's critical to enact comprehensive Medicaid reform to address the growing crisis in communities and to shift the financial incentives from institutional care to individualized flexible support systems for health promotion and health maintenance. One strategy for effective change has come out of Ohio. The health insurance task force of Ohio developmental disabilities council, has set forth a model of health care funding based on four principles: universal access to comprehensive health care without financial barriers must be the right of all American citizens; adequate health care must be provided through a unified system that meets individual needs; health care reform must retain private care delivery; and only a single payer system publicly administered can contain costs. We must establish and implement state and national priorities to assure that adequate and affordable health care is available to everyone. Much work has gone into the working papers on the prevention of disabilities. I feel honored to have the opportunity to read them and react.

My comments are grounded in the concept of self-determination and based on the independent living rehabilitation philosophy which I firmly believe in. The integration of this concept with the traditional medical model can only enrich the opportunities for greater numbers of individuals to not only survive but also to succeed in their efforts to stay well.

C. Education, Advocacy, Community Coalition

Robert Jecklin, M.P.H., Representing the Association of State and Territorial Directors of Public Health Education

My overall reaction to the working paper is favorable. Public health will benefit from the recommendations in the draft working papers. The recommendations on preventing disabilities due to adult chronic conditions will especially benefit the organization of public health promotion and education.

Data for Prevention Public health efforts to control chronic disease have always hungered for data beyond the body count. We have had adult mortality data for many decades; morbidity data have been available for several decades in the form of hospital discharge and primary care utilization surveys; and, thanks to the leadership of the Centers for Disease Control, we have several years of state-specific behavioral risk factor

data. Large scale epidemiologic studies of cardiovascular disease and cancer have told us more about these diseases and how to successfully intervene.

If one reads the literature in public health, the data that drive the planning of public health in the United States are clearly Old Testament mortality and increasingly new testament morbidity. If you go beyond the literature to the local level (counties, cities, districts), you see that local planners are still striving to interpret the old testament mortality and determine the meaning of newer mortality data for local public health action. It is very difficult for a local public health professional to use causes and frequency of death to shape local prevention efforts. At the local level, the use of morbidity data is confounded by limited availability and perverse funding incentives. Public health funding in the United States is a complex system of carrots and sticks designed by federal and state leaders to get local decision-makers to set local priorities "correctly." Although well-meaning, this confounds the use of local morbidity data even when data are available.

This draft working paper calls for creating additional epidemiologic data to steer prevention efforts. Because disabilities and the characteristics of disabilities occur more frequently than death, the epidemiology of disability prevention might provide the indicators needed to drive local public health practice and perhaps new public health funding approaches.

Another important benefit is the study of health, a subject long important to health educators. In a nation of "TV-dependent couch potatoes," does anyone really have a disability? To study the distribution and determinants of disability, epidemiologists will be forced to define health more than when studying a specific disease. (Disease-specific study has repeatedly defined health as the absence of disease.) I believe that the study of the distribution and determinants of disability will provide a mirror image of the distribution and determinants of health; we cannot say this about disease-specific epidemiology.

Accessing Available Services Public health traditionally utilizes education and regulation to achieve improved health status for communities. Increasingly the government is asked also to provide access to medical care; this function has overshadowed the traditional roles of many public health organizations.

Health educators are often asked to affect the utilization of services to prevent disease (e.g., immunizations) or intervene early (e.g., mammography). Most experienced health educators can tell you about disastrously successful education campaigns; utilization was increased for a poorly-planned or poorly-delivered service. For that reason, health educators annoyingly insist that educators and public representatives be included in the overall design and delivery of services.

Professional Education and Training Physicians and nurses will continue to push the limits of knowledge about disabilities, chronic conditions, and causal factors. The prevention role of primary care physicians and nurses will be strengthened in terms of referral to resources outside medical care settings and assuring a coordinated influence on the person. Allied health professionals should be trained in sufficient numbers today for predictable needs tomorrow. Professional education seems a very logical component to a public health approach.

Employers are open to education about improving organizational performance and, to a lesser extent, about investing in good work at a financial loss. This will require time and effort by experienced persons in organizational development; there is great potential for primary and secondary prevention efforts going hand-in-hand or even through the same staff.

Patient, Family, and Public Education Health promotion and education professionals would be most comfortable as part of a coordinated effort including primary, secondary, and tertiary prevention of disabilities. Communities, organizations, groups, and individuals will vary in perceptions of what needs to be done first - primary prevention, early detection and treatment, or rehabilitation. The best approach for educators is always to start with learner priorities. Increasingly educators and communities seek to change environments to be more supportive of health promotion and less supportive of disease causation. An example would be tobacco legislation to assure clean air in public places.

Unfortunately, the superior economic rewards of treatment, and to a lesser degree rehabilitation, dilute organizational commitments to primary prevention. Policy alternatives are needed to assure that rehabilitation, early detection, and primary prevention receive appropriate attention and funding.

Coordination and Advocacy The need for coordinated use of resources in every level and sector of the "what could have been" American health care system is paramount. A federal coordinating group for federal agencies is a great start. Deaths are recorded in a way that limits our understanding of the diseases affecting the deceased; this is not convenient for determining what program is responsible for preventing a death. Disability cuts across traditional cause-of death boundaries and forces us to look at the person who may have multiple diseases; with a disability focus, coordination across traditional boundaries will be prerequisite to progress.

The advocacy components of the draft paper have a welcome flavor. The recommendations emphasize interdependence between people, between systems, and between people and systems. An atmosphere of social support would be welcome after decades of cost containment, cost shifting, malpractice confrontations, access problems, widening disparities between groups, and sometimes unrealistic expectations of individual action.

Challenges to Coalescing Disability Prevention Coalitions The draft paper needs attention in several areas. Biomedical research is desirable but should not overshadow epidemiological data in importance. Will a constituency of energized persons with disabilities seeking new avenues of medical intervention support research to prevent disabilities in persons without disabilities? This is unlikely.

The evaluation of community health education interventions is an expensive proposition. Can a network of smaller interventions with more naturalistic evaluation designs supplant large scale controlled studies taking a decade or more to acquire results that may not be generalizable? Will a coalition support a narrow scope of activities with elaborate research designs? Centrally-directed, large scale, and complex evaluations would compete with areas of more tangible progress.

Coalitions organizing to improve the availability and accessibility of services to control disabilities will be shaped by efforts to resolve old conflicts - those who seek to concentrate wealth and those who seek to redistribute wealth, prevention resources and medical care resources, medical care resources and rehabilitation resources, the reasons to prevent disability and the reasons to accept and adapt to disability, and finally those who cause or profit from disability and those who want to prevent disability.

Lastly, I am concerned with the lack of recognition or clear statement about alcoholism and other drug dependence and social dysfunction. Because alcohol and other drugs are the responsibility of other organizations, we prematurely choose to keep these problems at the margin of public health. This will not last forever. Surely we recognize the role of these problems as disabling, or at least the role of substance

abuse in exacerbating other disabilities.

Perhaps social dysfunction is categorized as subclinical mental illness, but it is widespread and linked to other disabilities. Domestic violence, alienation, job dissatisfaction, political apathy, divorce, solo parents raising unwanted children, widespread discrimination, safety, and crime all suggest a breakdown or failure to achieve the beneficial synergy between individuals and society.

Again, I congratulate the committee on an exciting start to what I view as a very hopeful shift in focus for public health. We in health promotion and education look forward to the opportunities created by this shift.

Linda Tonsing-Gonzales, Director, New Vistas Independent Living Center

When I was asked to review the Working Paper on the Prevention of Disabilities Due to Adult Chronic Conditions, I knew the subject matter would be of a personal as well as professional interest to me. However, as I approach the subject, prevention of disabilities due to adult chronic conditions - I wonder where I fit? The working paper defines chronic conditions as diseases and syndromes of extended duration. I have a condition that is certainly chronic, but medically, that condition is classified as a developmental disability. At age 16, I was diagnosed with facioscapulohumeral muscular dystrophy after two older brothers were found to have this particular hereditary disease. However, I was well into adulthood (about age 27) when symptoms began manifesting. Hiding and denial were no longer adequate coping mechanisms for me. Through the years, I always walked the line between able and disabled, between hidden and visible disability, between the pseudo acceptance of passing as "normal" to the subtle prejudice of appearing "different."

Living day to day with increasing limitation in arms, legs, stamina; living with the frustration of being out of control; wondering if prevention techniques work for me? Many of us feel we're the exception to the rule - on getting better or getting worse. Does exercise help or hinder? Will special diets or vitamins slow the inevitable? Common sense says it's worth the risk to try. If we try and we fail, we feel angry and frustrated; if we don't try, we feel guilty. And yet we can't let ourselves become so involved in trying to control the uncontrollable that our self-focus excludes the value of selflessness - turning outward to helping others.

I have always been fascinated by the term "disease." Disease moving forward even when outwardly health appears to abound. Disease with some sub-level activity that we picked up from the air or from our parents. Genetic codes half malfunctioning at microscopic speed. Intrigue and respect for the complexity of life and its idiosyncrasies. At the human level, manifestation is slow: a drop foot, a flaring shoulder blade, the inability to whistle. Symptoms pile up, impairments accrue, disability's inevitable.

I have contemplated the mystery for hours; gotten furious at the ineptitude of the "experts;" longed for the abilities that have now escaped me; envied the passerby who can walk unimpeded. But, if there is some esoteric reason for being in the condition I am in, (which really is comparably mild to other children and adults more severely involved with MD than I am), it is that it has led me to the field of independent living. Having been in the field for nearly a decade now, my profession is an area where I can excel, work hard, not be judged on my physical prowess, and most importantly, be involved in a major societal movement that is changing the lives of people with disabilities. It is from a mixture of this personal and professional perspective that I will proceed to review this chapter. I feel privileged and honored to have a part in the formulation of a national plan of education and prevention of primary and secondary disabilities.

Response to the Background of the working paper

Chronic Conditions

While the working paper claims to focus on the prevention of disability due to chronic conditions with onset during adult years only, it appears to include only those more traditional conditions like cardiovascular disease, cancer, chronic obstructive pulmonary disease, diabetes, osteoporosis and multiple sclerosis. As in my own case, and perhaps other types of adult onset muscular dystrophy and post-polio, consideration should be made to include prevention techniques that could slow the disabling effects of diseases that have a progressive prognosis, and of preventing secondary disabilities that are at risk, when the primary disability does progress. The fact that age increases the risk for both primary and secondary disabling conditions is not limited to the elderly in such cases as described above.

And the fact that data do not exist for the impact of disabilities on middle-aged individuals makes recognition of these groups especially important when conducting such surveys.

Racial Ethnicity and Disability

The fact that the "prevalence rate of chronic conditions is higher among whites than non-whites . . . (but the) disability rate among non-whites is much higher", certainly suggests to me that whites have greater access to better health care than non-whites. These factors include whites having a higher economic level, better jobs with health insurance benefits, less prejudice for services at more hospitals and health care centers, and better education resulting in improved self-care.

Ethnic and racial minorities are more often than not relegated to free clinics, county hospitals, the limitations of Medicaid or Medicare, ghetto-like health care systems (like the Indian Health Service) or indigent care. By the very nature of our current health care system that emphasizes risk coverage for providers, high insurance premiums for patients, quick in and out care for the underinsured, and exclusive service options for private pay insurance, it is no wonder that minorities are paying the price. If for no other reason than this fact of greater incidence of disability (added to all of the other societal handicaps), the entire health care system needs an overhaul.

While neither exclusively racial nor ethnic, attention should be paid to the health care crisis in rural areas. American Health Association studies indicate that rural hospitals in 1986 represented 46 percent of the nation's community hospitals. They are losing money at record speed, reporting negative net patient margins, placing greater reliance on Medicare revenues, and experiencing rising rates of uncompensated care. Almost one-third of the nation's uninsured live in rural areas. Thirty-seven rural hospitals closed in 1986, 19 of which were in Texas. Lower federal payment rates, along with increasing competition from large regional medical facilities, are forcing rural residents to ignore health care problems because of the expense and inconvenience of seeking care outside their community.

Secondary Conditions

People with chronic conditions are at greater risk of developing secondary disabilities than those with acute conditions. That these secondary conditions occur because of "increased risk of inadequate knowledge, monitoring tools, and access to appropriate health care", seems a sad comment on the decades of medical advancement, the thousands of physicians educated and trained and the millions of dollars poured into research efforts annually. I have yet to meet a doctor whom I can honestly believe knows more than I do about my disease. And I'm not just talking about my local family physician. I recall one visit to the Neuro Muscular Clinic at a neighboring city hospital when I was inquiring into the benefits of exercise for myself. I was over forty, had put on about twenty pounds, and as my hip girdle muscle weakened, I was plagued

with a protruding abdomen. My doctor, the chief internist, said it would run its course after being checked and rechecked. There is considerable adjustment to be made, not just in the areas of time, energy, and emotion. Environments need re-evaluation and modification, as do values, self-image, determination, purpose in life, etc. It is encouraging indeed to see that the importance of independent living has emerged as a major theme of this working paper on adults with chronic conditions. It is especially important because with chronic conditions, typically the disabling process is slow, encouraging one to hold on to old self-images, memories of better health, and unimpaired ability. Living in a society that glorifies the "body beautiful" image and abhors the thought of disability (i.e., living as a person who walks differently, talks differently, moves differently, hears differently or thinks differently), can be quite difficult. It certainly impedes a person's ability to get on with life and make the adjustments needed to live life as he or she chooses.

The term "independent living" has not been defined in the working paper, or in the definition of terms in the Introduction. As a long-time advocate in this particular field, I would like to suggest it be defined herein. Too often, new terms catch on like a brushfire and are used to gain access to funding resources - without passing the litmus test for legitimacy. What makes independent living centers (ILCs) different from other social service agencies, other rehabilitation facilities, and other health education? One independent living service in particular, peer counseling, has been mentioned repeatedly in the Effective Interventions section of this chapter - and rightfully so. It is the cornerstone of independent living and, along with advocacy, is what independent living is about - people helping people.

I believe that "institutionalization" is not so much "a consequence of the failure to prevent disabilities" as it is a consequence of our current societal priorities (i.e., in 1987 $41.6 billion was spent on nursing homes and less than 10 percent or $27 million on independent living centers). The average cost per year for living in a nursing home is $30,000, compared to an average cost for attendant services of roughly $8,000 (from National ADAPT).

As long as the medical model prevails in areas where it may not be necessary - and where community-based providers could better serve - the imbalance will continue. Lack of adequate funding for appropriate support services in the community is the major cause of inappropriate placement in institutions.

If prevention is truly a shared responsibility, I believe there is a wide gap to close between the professionals treating patients and the people helping people models. Besides identifying community resources, the huge multi-billion dollar health care industry (from the private home health agency, to the for-profit rehabilitation facility, to the health insurance industry) will all have to dip into their coffers to realize these idealist goals of medical and community partnerships.

Response to the Prevention Strategies presented in the working paper

A. Research: Epidemiologic, Biomedical, and Evaluative

This is not my area of expertise, but again I would question if data are being gathered on adults with onset of genetic disabilities and recurrence of childhood disabilities like post polio?

Correction in GAP 4 - Independent Living Centers are funded through Rehabilitation Services Administration (RSA) not NIDRR. Both federal agencies are mandated under the Rehabilitation Act of 1973.

Program evaluation of independent living centers has been a long-standing issue, with evaluation indicators still to be forthcoming from RSA. In the meantime, the minimal research done on these centers indicates that most are serving a wide range of disability groups and providing a variety of services at minimal cost. Measurable results (i.e., cases closed, goals achieved, etc.) are difficult to assess because quality of life improvements are often intangible, delayed or unrecognizable as such. One rather broad measure of the success of the independent living movement is the phenomenal advances made by people with disabilities in the last 10-15 years. We were all "handicapped" back then. We were not considered as having significant input into planning events such as this conference, and we were much less visible in the community. The success of ILC's is best measured in the visibility, in the regaining of respect and self-respect, and in the ability to meet the challenges life presents to all its participants.

When evaluating models used to effectively manage chronic conditions, don't forget to evaluate peer counseling/peer support (or the buddy system as it is referred to herein). This model too is based on the Alcoholics Anonymous (AA) peer approach.

Guaranteeing that work disincentives will be eliminated, at least in areas of medical insurance, is already being addressed by the Social Security Administration.

In my opinion, it would be more beneficial for a worker with a disability to be able to pay insurance premiums to maintain his Medicaid or Medicare while working, and retain these benefits automatically when not working at no cost. Loss of medical benefits is the major deterrent to people returning to work. Even if private insurance would offer comparable benefits, which it does not, the threat of losing a job or becoming unable to work again and having to reapply for federal insurance coverage is not a favorable prospect for the potential worker.

GAP 3: Access to culturally appropriate services is a critical need. Technical assistance should be provided by knowledgeable members of the cultural group. In some cases even non-traditional methods or systems should be considered when they are viewed as relevant within the cultural context, i.e., healers and medicine men.

C. Availability of Services

GAP 1: Besides assuring the availability of professionals such as registered dieticians, health educators, community health nurses and visiting nurses; independent living center staff, peer counselors and personal services attendants should also be made readily available and reimbursed for their services.

If adults with chronic conditions and disabilities are only exposed to the professional and treated as patients, they will soon assume that dependent, child-like role of being told what to do. ILC intervention will teach them how to advocate on their own behalf, how to be an employer of an attendant, not a helpless patient.

GAP 2: The paper recognizes the role ILC's can play as an innovative program to prevent disabilities, but Gap 1 should recognize the role the ILC can take in transitioning a person back into his or her community from a hospital, institution or rehabilitation center.

Because independent living encompasses every facet of a person's life, the ILC is the ideal coordinating

hub for all types of services: from housing, to home health or attendant services, to employment, to vocational rehabilitation, to mental health services, prevention, self-care, modifications in the environment, etc. Being broad-based, the ILC information, referral and resource identification capabilities exceed other more traditional single focus, or single disability, organizations. The added benefit of utilizing people with disabilities, professionals, paraprofessionals, and volunteers, makes the ILC an invaluable resource to the health care industry.

Again, in the strategy to increase home health services if they are "going to go" a long way to assuring maintenance of independent living, they had best be rooted in the consumer control philosophy. Congregate housing opportunities should be supported only if they are a part of mainstream housing. Any grouping or ghettoizing of people with disabilities will only slow the progress of total integration and perpetuate negative stereotypes and myths.

D. Professional Education and Training

GAP 1: Certainly it is important to recruit minorities and people from rural areas. But, is it likely these people will return to unattractive salaries and poor working conditions? Not to belabor the point, but how about the wild idea of people with disabilities being recruited to become doctors, nurses, clinicians? Do our high schools encourage a student in a wheelchair or one who uses sign language or a guide dog to pursue their highest dreams? Why aren't there more Steven Hawkins or Izak Perlmans? One of my most encouraging moments was when I discovered a researcher (Ph.D.) in southern California who was researching the genetics of FSH-MD, who actually had the disease himself! Now that gives me hope!

GAP 2: The strategies listed in this section on adequate training of professionals are crucial to responsible health care. While it is certainly a recognized fact that acquiring the wealth of knowledge necessary to become a physician is a formidable task, there does seem to be some glaring gaps in the education process.

In addition to the recommendations put forth as identified needs in curriculum, I would like to add early and regular exposure to people with all types of disabilities. This suggestion would emphasize meetings in informal, nonclinical settings. Because people with lifelong disabilities also need general care, physicians need to be able to interact and provide services without discomfort. Again, independent living center staff can help to bridge the gaps between physicians and patients with disabilities. Not only do myths and stereotypes need to be dispelled, but also education about accessibility in the medical office needs to be provided. I know of a physician in southern New Mexico, a female family practitioner, who limited her practice to only people with disabilities and their families. She took great interest in being a provider that offered accessible exam tables and weighing scales, Hoyer lifts, wide doorways, etc. She provided lots of health care information and referral to community-based programs as needed. She had a wonderful rapport with her patients, and everyone in town wanted to be a part of her practice. While this is a step in the right direction, it would not be the road to follow special physicians serving "special" people. Every physician should have the knowledge, rapport, and accessibility that she had. She should not be an exception, but the rule.

E. Patient, Family, and Public Education

GAP 1: Public awareness of people with disabilities continues to grow in a positive direction - witness the last few years of Academy Award winning films like Rain Man, My Left Foot, and Born on the 4th of July.

Similarly, people with disabilities are subtly being slipped into commercials as part of mainstream life.

Relating to public figures who "admit to having a chronic condition or to using adaptive devices" is a successful way to promote role models. But equally important is promoting the housewife with a disability, the man down the street who is blind, or the high school student who has cerebral palsy. In other words, don't overlook the value of "peers."

People with disabilities have not always benefited from the "rise above overwhelming circumstances to hero status" like Helen Keller, F.D.R, or Beethoven. In reality, most of us will never be national heroes or public figures. If we learn to adapt to our limitations and 'find our niche in life, it is not because we are "super people." People with disabilities, as well as the non-disabled, must realize that we're just a slice of mainstream: some high achievers, some low, some handsome and pretty, some average or plain, some successful, some failures, some rich - most poor!

The majority fall into the category of average, and it is an okay place to be. When you hear people with disabilities wanting to play down the "special" category that society loves to place them in (special education, special needs, special olympics, very special arts), it's not much better than being lumped into "handicapped." We'd rather be merged into the mainstream and lose ourselves in the crowd. Given a truly accessible, supportive society, this could happen. If the independent living movement is truly successful, centers will eventually fade away as total integration fully occurs.

GAP 2: More and more health professionals, especially at rehabilitation centers, have recognized the value of utilizing the services of ILC's and in particular, peer counselors. An example of such a partnership is St. Joseph's Hospital Rehabilitation Center in Albuquerque. Occupational therapists and emergency medical technicians from St. Joe's participate in the ILC attendant training program. They provide the more technical aspects of training: transfers, bowel and bladder care, health maintenance, CPR, first aid. The ILC provides the aspects of training that relate to the employee-employer relationship. Trainees learn first hand from an attendant users panel what is expected of them and what related problems and issues to expect. At the same time, attendant users are taught skills to assist them in managing an attendant and caring for their health and daily living needs. St. Joe's soon began including family members of rehabilitation patients in the attendant training. They received so much benefit from ILC-provided peer counselor services that a joint support group was started. Eventually the rehabilitation center hired its own peer counselor.

F. Coordination of Services

GAP 1: National coordination. The interesting outgrowth of independent living is that it has brought together many disabilities that have in the past been fractioned for one reason or another. It has made us recognize that our similarities are greater than our differences, and that at some level, we all face societal barriers - be they environmental or attitudinal.

As a result of decades of advocating by special interest groups, the federal system has come to be a huge bureaucratic mechanism that includes multitudes of acts, agencies, and administrations. *Towards Independence* listed 44 federal agencies that provide services to people with disabilities. Multiply that number by 50 states and you have 2200 bureaucracies. Add to that figure tens of thousands more for-profit and not-for-profit providers, all trying to please those state and federal agencies, trying to get and keep the monies. Each of these agencies has its own turf, its eligibility requirements, its funding mechanisms, its

administrations, and particular population to serve. This fractured system has trickled down from the federal to the state and local levels, and all systems are strongly influenced by the power and money of special interests.

Is it impossible to ever hope for any order out of the chaos? Imagine the consumer already overwhelmed with the circumstances of life, trying to maneuver through the very "system" designed to help him.

Independent living has brought some continuity to the madness - at least helping to clarify the situation. People need the basics: a house, a job, health care information, perhaps personal services (such as attendants and home health aids),, perhaps skills to live more independently, and total access to their community. Perhaps they need readers or interpreters, or a friend in a similar situation who can relate to the events and feelings of living with a disability in America today.

What if there were one National Office on Disability with divisions to address each of the above? What if there were only one disability determination unit and a one-time eligibility that qualified a person for any or all of the above services? What if case management were minimal for those who don't need it and adequate for those who do? What if no one fell through the cracks? What if "medical care" were included as an inalienable right? What if, with all the streamlining of administration and management, the dollars freed up were actually going to the person who needed them? What if institutionalization and any type of segregation were outlawed?

I realize the ideas are absurd; millions of people would lose their jobs, dynasties would fall, capitalists would collapse. Though human beings are bottom line, we're dealing with big business. And, while utopian ideas could make the difference between life and death, unfortunately it will probably continue to be business as usual.

G. Advocacy

GAP 1: The findings in this gap are a logical consequence of the aforementioned system. "Individuals with disabilities due to chronic conditions are often left to fend for themselves. They may find themselves faced with having to negotiate a complex medical care and social services system. . ." The conclusions of the authors of this chapter are my own as well. Instead of a major revolution (or until one is instigated), utilize the independent living centers.

Not only do ILC's advocate on an individual and a systems level, but the independent living model teaches people to advocate for themselves. The process has been phenomenal. Systems are changing, becoming more responsive and less bureaucratic. People are speaking out in front of buses, from nursing homes, before legislators and national leaders. There is no turning back. We were given an inch, a taste of freedom and independence, and we want to go the whole mile.

People with head injuries, with psychiatric disabilities, people who are quadriplegic, mentally retarded, people with MS and MD and CP and environmental illness. People with chronic conditions, disabled Vietnam veterans, the hearing impaired, the blind and visually impaired - they are most definitely speaking out and they are being heard. It will behoove every professional who is looking to provide services, looking to turn a profit, looking to aid mankind to stop and listen, to listen to people with disabilities who are no longer part of the problem but part of the solution. Are you?

Response to the Implementation of Strategies

I wish to express my appreciation to the work group that developed this chapter on Prevention of Disabilities Due to Adult Chronic Conditions. It provoked me to thinking and stirred feelings stronger than I realized I possessed. Such reaction is good.

I agree that there are challenges to implementing such a national plan. I've been on too many task forces and advisory committees where good reports and great ideas lay gathering dust on some bureaucrat's bookshelf. It seems like so much money keeps being poured into research and training, gathering data, disseminating information, and identifying model projects - and nothing seems to progress. If nothing else, could we find a way to fund more direct services? Can't we find more resources for the long waiting lists, even if it means calling on the large charitable organizations that raise millions of dollars for "research?" Cures mean little to the person saddled with disease or disability on a day to day basis.

<u>Brian Williams, M.D., Georgia Department of Human Resources</u>
I would like to commend the authors for what seems like much time and effort spent in putting these facts together. Problems were tracked and managed, but there is another side that we must be constructive, so that our implements will foster growth. I'm going to base my reaction on the thought that a person generally sees what he or she searches for.

Gap: Inadequate epidemiological data. The first gap addressed correctly states that there are inadequate epidemiological data on populations with disabilities due to chronic conditions, and proposes as one of the strategies to expand the surveillance systems to collect more accurate data on underserved groups. We all must agree that data in all its forms are necessary, but we must be careful in our endeavor to gather more accurate data. The accuracy of data is measured not only by methodology, but is also influenced by the state of mind. And by state of mind, I mean the subconscious bias or objective of the person collecting the data, whether they be for research or the computation of numbers. Because there again, you're going to find what you're looking for.

Gap: Inadequate biomedical research. This correctly identifies an insufficiency in biomedical research to identify specific clinical relationships between primary chronic conditions, their related conditions, and causally-induced secondary conditions. One of the strategies proposed is to increase the participation of minority populations in clinical trials, and analyze findings to determine specific effects on minorities. Here I believe great care should be taken in implementing this aspect of promoting minority participation, since the targeted group could be perceived as guinea pigs.

Gap: Expanded research on adaptive technology and self-monitoring tools. The expansion and research on adaptive technology and self-monitoring tools is indeed a demand; however, we have to be careful in our attempt to develop these devices that we are not transforming persons into mechanical instruments or devices to function the way we think they should perform and thus deprive them of their potential. We should see disability as a consequence and not as a disease interfering with the disabled's intelligence quotient.

Gap: Insufficient availability of services. A strategy is also proposed to improve the physical access to screening, treatment and prevention services, through improved transportation services that are free from crime and not economically prohibitive. Whereas access to preventive services by means of improved

transportation services is of paramount importance, we can not overlook as a primary objective making it conducive and compatible for the person with a chronic disease to not only get into the facility physically, but also to gain unbiased and equal access into the system. He should be accepted as an individual with uninterrupted motivation. Although access to care is indispensable, quality should never be compromised for quantity. I felt that the strategy of mobilizing and increasing access to community services and social support groups is not adequately addressed. It was also documented that minorities are disproportionately and more severely affected by chronic diseases and more likely to suffer a severe disability; therefore, this aspect should have been dealt with in more detail.

Gap: Professional education and training. A point of great importance, and for which the authors should be highly complemented, is the section dealing with the training of professionals and employers. This is an indispensable ingredient in the understanding and management of people with individual needs.

Gap: Advocacy. The establishment of advocacy groups is in many cases necessary, but the goal should be to develop an educated society in which the disabled will enjoy free and equal access to all that is available. There were good comments throughout the article; however, there needs to be more focus on identifying predisposing conditions to disabilities as a result of chronic disease and preventing these. It is known that minorities are predisposed to certain chronic diseases that eventually can lead to disability. The question is, how does one effectively get the message across on how to identify and minimize the effect of predisposing factors that commonly lead to disability? Society has never looked on or accepted individuals with disabilities in a positive light. I'm not sure this chapter addressed this point sufficiently; then again, that may not have been the goal. If it was not, why not? As a part of education we need to get away from emotionalizing needs of individuals with disabilities. Where coalitions are important is in the formation or pulling together of different groups, the public sector, the private sector, and users of services as partners. This concept is a workable one and has been known to work with great success in areas of hopelessness in great cities across the nation.

In talking about building coalitions, the building blocks are not static. It is necessary to involve different groups, traditional and not so traditional, in the process of planning, since experiences learned by one group are readily transferable to another group in many instances. Finally, although it can be sometimes difficult to separate prevention and treatment, I would've liked to see more emphasis placed on prevention, since as was adequately stated by the authors, it is much more cost-effective to prevent disability than to treat it.

<u>Margaret Chase Hager, Member, National Council on Disability</u>
On behalf of the National Council on Disability, it is a privilege to be with you today. We have the shared responsibility of formulating prevention into national policy. I wish to thank the Centers for Disease Control, the Minority Health Professions Foundation, and the National Institute for Disability and Rehabilitation Research along with the Council for cosponsoring this Conference. I wish to commend numerous authors for their valuable expertise in producing the *Draft Working Papers on the Prevention of Primary and Secondary Disabilities.* Together with the reactions, this is a tremendous accomplishment.

From my perspective, my reactions to the "Adult Chronic Conditions" focus on individuals and the effect of education, advocacy and community coalitions in promoting individual abilities and preventing disabilities. My comments are presented with the intent of expanding the comprehensive effect of the document. They are arranged in a fashion to focus on the following:

Who are the adults and what happens to their character and personhood as they experience illness and disability?

How do their lives change with the onset of illness? How can their personal energies be turned around toward productive goals?

People make progress. Only in understanding people with disabilities can we see that programs such as prevention become successful. Young adults look forward to success in the big world. They have hopes and dreams, energy and optimism, family and vocational goals. They are part of the process. With the onset of chronic conditions leading to disabilities, sensitivity is heightened. Suddenly familiar worlds close down. Relationships with family, friends, community and vocation are threatened. Instead of caring, he or she is cared for; instead of planning, he or she is being planned for; instead of achievements, there are barriers - physical, mental, and attitudinal.

Less flexible than a child, an adult rejects being pushed and pulled around. Choices are diminished. Personhood dwindles and disability becomes the overriding definition. Communication breaks down and often becomes a one-way process. There is a dramatic change in lifestyle, life roles and responsibilities, life relationships. Moreover, it is known that 35 million Americans who are 65 or older make up 13 percent of the population but account for 44 percent of all days spent in the hospital. They are a third of the nation's health care expenditures.

Every effort must be made to reverse these trends. Efforts and resources must be made available for people to:

- Regain productivity and self-esteem
- Rebuild personal relationships
- Create new alliances
- Express new abilities.

Along with research and services, people must take individual initiative and action in the prevention agenda. Government cannot do it all. We need to promote common sense solutions. People with disabilities and their families have an absolute right to determine their future.

Turning now to the Working Papers. As I read them, two modes of operation become evident: the Prevention mode or "before disability" and the Treatment mode or "after disability." The term service is used generally in the Working Papers without clarifying either prevention or treatment.

In a recent newspaper article, Dr. Walter Ettinger, a geriatrician at the Bowman Gray School of Medicine in Winston-Salem, states, "I had a 79-year old lady, sharp as a tack, who used a wheelchair and was incontinent when I met her. She had pains in her knees and early Parkinson's disease, which made it hard to walk, and was taking diuretics for her high blood pressure, which made her wet herself because she couldn't get to the bathroom, and without exercise, she had put on weight, making it even harder to get around." Dr. Ettinger found that the knee pain was treatable bursitis; likewise, the Parkinson's and weight gain were treatable. The woman was ultimately able to walk and use the bathroom. According to Dr. Ettinger, "Like most of our patients, it wasn't that she had had terrible treatment, but no one else had the time to think about her problems or the resources to try to restore her functions." For everyone, for people with disabilities, it is necessary to have overall understanding and treatment; for chronically ill individuals, it

is essential.

Turning now to local community examples of education and advocacy for prevention, let me present several examples from Richmond, Virginia, which promote opportunities for people with disabilities to participate in health, vocational and community activities. They are bridging the gap of understanding between the medical world and the disability world:

- The Adult Development Center, an agency of United Way
- The Richmond Association of Retired Citizens
- Action for Prevention, Inc.
- ABLEFEST I, II and III, termed "abilities festivals," coordinated by the Richmond Mayor's Commission for the Disabled to promote prevention and wellness.

They are community endeavors which respond to and provide participation of individuals with chronic conditions and disabilities in the health and wellness process through activity and performance.

In closing, let me share with you a quotation from the ancient Greek mathematician and inventor Archimedes. It reinforces a common credo for all of us here today. He says, "Give me a place to stand, and I will move the world." The word "stand" in our understanding takes on more than simply a physical reference; it is the moral, mental and spiritual strength of an individual. I can express responsibility. I care. I can be a part of the process. I can make a difference.

COMMENTS ON THE WORKING PAPER

Prevention of Disabilities Due to Adult Chronic Conditions

General Issues/Background

The scope of the paper is too narrow and should be expanded to include the long-term disabilities that result from chronic conditions with onset in childhood.

2. Most of the increase in the age-adjusted incidence rate for all cancer sites combined is due to the increase in lung cancer death rates. Lung cancer is the number one cause of cancer death in men and women, yet it is not mentioned in the paper.

3. The emphasis on primary prevention of chronic conditions needs to be strengthened. The discussion on the importance of primary prevention, should be moved earlier in the paper so it is not overlooked. More funds are needed for service, research, and training in this area.

4. Consideration should be given to including prevention techniques that could slow the disabling effects of diseases that have a progressive prognosis, and of preventing secondary disabilities that arise during that progressive process. The fact that age increases the risk for both primary and secondary disabling conditions is not limited to the elderly. The lack of data on the impact of disabilities on middle-aged individuals makes recognition of these groups especially important when conducting surveys.

5. The paper should explicitly state that higher prevalence rates of disability among nonwhites than

whites suggests that whites have greater access to better health care than non-whites. The access problems in rural areas should also be mentioned.

6. Additional data on Hispanic Americans could be added to strengthen the section on Race/Ethnicity and Disability. For example, while Hispanics get cancer less frequently, they are three to five times more likely than whites and blacks to develop adult-onset diabetes and its complications. In addition, while Hispanics account for only 7.9 percent of the U.S. population, they represent 14 percent of the AIDS cases nationwide.

7. The text of the paper contains some definitional ambiguity that should be corrected:

   - Tables 1 and 2 include some chronic conditions of childhood-onset (e.g., mental retardation).

   - The definition of secondary condition is not clear enough.

   - The paper should encourage modification of the definition of health to focus on a person's actualization of potential (or "functional health") rather than freedom from illness.

   - The term "independent living" needs to be defined. The definition should build on the philosophy that given adequate support services, a person with a disability will choose to live independently. It should also mention the commitment to involving a majority of persons with disabilities in the planning and delivering of services.

   - The terms "culture," "ethnic group or ethnicity," "race," and "social class" should be defined and clearly distinguished. Proposed definitions are as follows:

     Culture the learned patterns of thought and behavior that are characteristic of a society or a population.

     Ethnic Group or Ethnicity a distinct category of a population in a larger society, whose culture is different from that of the larger society.

     Race a major subdivision of humankind having a common origin and made up of individuals who have a relatively constant combination of physical traits that are handed down from parent to children.

8. Tables 1 and 2 show the leading chronic conditions for all ages and should be replaced by tables showing the leading chronic conditions by age and gender (Verbrugge, 1990). Such tables would be more useful in identifying the relative rankings of conditions (see Attachment IV-B).

10. The example that suggests that men cannot sweep floors and clean bathtubs as well as women should be corrected.

11 Populations of Americans who have end-stage renal disease, autoimmune disease (such as multiple sclerosis), and "orphan diseases" should be included.

12. The paper neglects to emphasize the importance of tobacco in relation to chronic disease. This could

be corrected by:

- Adding a tobacco component to each of the seven Prevention Strategies or adding an eighth strategy to specifically focus on reducing tobacco use.

- Mentioning smoking as a risk factor for high blood pressure. The Framingham study shows that smoking is a more important risk factor than hypertension in the etiology of coronary artery disease; yet, smoking is not even mentioned in this paper. Smoking should also be included as a risk factor for stroke and osteoporosis.

- Listing smoking, or substance abuse as a chronic condition on Tables 1 and 2.

- Stating that smoking prevalence is higher for several racial/ethnic groups, leading to disproportionate mortality rates for lung cancer and other tobacco-related pathologies.

13. The paper needs a discussion of involuntary infertility or subfecundity. This chronic condition leads to the disability of forced childlessness and may be accompanied by repeat miscarriages or other recognized adverse reproductive events. Of the approximately 15 percent of all couples who are involuntarily sterile, 6-30 percent have no recognized reason for their childlessness. Male sterility from occupational exposure to the nematocide dibromochloropropane (DBCP) is one of the most dramatic examples of occupational impact on the ability to father/conceive a child. A larger number of couples conceive with various degrees of difficulty. New reproductive epidemiologic methods can now be used to evaluate adverse conditions contributing to that difficult, such as lowered semen quality, increased time to conceive, and increased subclinical pregnancy loss. Occupational and environmental exposures have been shown to affect these measures in epidemiologic studies.

14. Comments on the attached tables are as follows:

- The examples need a better balance across body systems. To help achieve this balance, an osteoarthritis example should be added (see Attachment IV-C). In addition, the examples should include lung cancer rather than colo-rectal and prostate cancer, since screening for these latter two forms of cancer is not effective. Smoking cessation should be listed as the primary prevention strategy for lung cancer.

- The format of the attached examples is confusing. There is too much information presented in a small space. Also, the difference between pathology and impairment seems artificial, as does the distinction between functional limitation and disability. More specific information about the manifestations and interventions would be helpful. An alternative format would consist of narrative questions and answers to assist the reader in learning about prevention strategies throughout the disabling process.

- More attention is needed on chemical dependency and mental health issues as adult chronic conditions that cause much disability.

- The listing of secondary conditions in the attached examples should be expanded to be more complete and accurate. For example, tinnitus should be listed as a secondary condition of hearing impairment.

- The example on Sensory Conditions should include mention of workplace hearing conservation programs as an intervention. Occupational injury should also be listed as a secondary condition.

15. The paper should state that institutionalization is a consequence of current societal priorities (e.g., large expenditures on nursing homes), rather than a consequence of the failure to prevent disabilities.

16. The paper should encourage the National Council on Disability, the Centers for Disease Control, and the Minority Health Professions Foundation to strengthen their relationship with the Office of Minority Health in support of health rights for all persons.

17. The national plan should be developed in cooperation with public and private insurers and should emphasize personalized, individualized care delivery.

Surveillance, Epidemiology, Data Needs and Sources

1. The paper is vague and could benefit from more specifics and examples. For instance, existing data sources could be listed along with an analysis of their respective strengths and weaknesses.

2. More emphasis should be placed on research that targets primary prevention of common diseases such as coronary artery disease, Type II diabetes, chronic lung disease, and chemical dependency.

3. Although biomedical research is desirable, it should not overshadow epidemiological data in importance.

4. The paper may be weighted too heavily on scientific and research strategies. A higher priority should be assigned to the strategies involving service delivery.

5. The paper correctly calls for increasing participation of minority populations in clinical trials, but should urge that care be taken to avoid the perception that these populations are “guinea pigs.” In addition, the paper should reiterate the validity of conducting research studies on only one race and/or gender.

6. Special funds should be created for research in minority groups who bare the burden of higher morbidity and mortality rates. More accurate data is needed not only on minority populations but on groups of differing socioeconomic status. Data collection should be designed to avoid bias.

7. More research is needed to identify:

   - The factors that predispose persons with chronic conditions to develop disabilities.

   - Strategies for improving society’s acceptance of persons with disabilities.

   - Valid and useful methodologies for identifying and measuring psychological and social risk factors associated with disability.

   - The functional capacity of persons with chronic conditions and the implications of that capacity for the design of safe levels of work. For example, for persons with mild chronic obstructive lung

disease it would be useful to have precise criteria for determining who should be excluded from work which requires use of respiratory protection.

- Effects of peer counseling/peer support on persons with disabilities.

- Strategies for promoting health and healthy behaviors. These strategies should recognize the variety of population segments that exist in the U.S. and should be tested rigorously. As much, if not more, effort should be directed towards selling health as is currently directed toward selling disease (e.g., by tobacco companies).

8. Use of personal identifiers in hospital data, such as social security numbers, should be explored so that data bases can be linked and compared. Confidentiality should be

9. The evaluation of community health education interventions is an expensive proposition. A network of smaller interventions may be able to provide generalizable information in a shorter time frame.

10. Specific comments on surveillance are as follows:

    - The paper states that no comprehensive data exist on the numbers and types of functional limitations and disabilities due to chronic conditions. This may not be entirely true, since much information on underlying risk factors can be obtained from the National Health and Nutrition Examination Survey (NHANES), the National Health Interview Survey (NHIS), and the Behavioral Risk Factor Survey (BRFS). These surveys and relevant data should be cited.

    - Surveillance systems should be expanded, but should also define an Hispanic race group. Although it is customary to present surveillance statistics on racial differences in disease, those variations can be mostly accounted for by differences in income, risk factors, and access to medical care.

    - The paper should include a description of new surveillance systems that are needed and how they might be implemented. Specific information is needed on how to gather prevalence information on conditions that are seen primarily in outpatient settings.

    - The paper states that current surveillance systems can estimate the number of arthritic patients in the U.S. This statement may not be accurate.

    - Additional data are needed on adults with onset of genetic disabilities and recurrence of childhood-onset disabilities like post polio.

11. Conducting population-based surveys in outpatient settings may be difficult. Sampling may be a more useful method for defining prevalence. Data must be collected from a large enough sample to derive population-based rates.

12. A gap should be added to reflect the lack of scientific testing of the validity and reliability of the Model of Disability (as described in *Disability in America)* and other models in explaining the disability phenomenon.

13. Analysis is needed to compare the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) model of disability with the model described in *Disability in America.* An attempt should be made to resolve any differences between these two models so that all data collection and research throughout the world will be using comparable definitions and nomenclatures.

14. One reviewer felt that prevention impact statements, if required, should be incorporated into the application procedure for grant awards. Another reviewer called for the deletion of this strategy since the burden of this strategy would likely fall on researchers who seek federal funds, adding another administrative hurdle to their research efforts.

15. The funding source for Independent Living Centers should be changed to the Rehabilitation Services Administration (RSA), rather than NIDRR. Both federal agencies are mandated under the Rehabilitation Act of 1973.

Access to Care, Quality and Coordination of Care, Financing

1. The paper should more directly address the issue of changes needed in the composition and structure of the nation's health care system. Revamping this system is essential for effective prevention of disabilities.

2. An additional gap should be added under Access to Services, addressing the lack of motivation among persons with disabilities to seek appropriate services. Strategies would include the promotion of shared responsibility between the person and the professional, and the joint development of a "wellness" plan to include when and how to seek health services.

3. Access to culturally appropriate services could be enhanced by requiring community-based organizations (e.g., independent living centers) to establish governing bodies that include and represent all segments of the population served. Outreach to increase minority participation should also be a requirement of funding.

4. Single-point access to care should be promoted to improve the ability of persons with disabilities to receive the care they need. This access should be guaranteed regardless of previous employment status and ability to pay.

5. Augmentative and alternative communication devices should be included under the second section of strategies.

6. Current strategies for service delivery need to be assessed to identify those that should be replicated.

7. The role of independent living centers in fostering a healthy relationship between persons with disabilities and the health care community needs to be explored. The paper should recognize the role that independent living centers can play in coordinating all types of services - from housing, to home health or attendant services, to employment, to vocational rehabilitation. The availability of independent living center staff, peer counselors, and personal services attendants should be promoted. Adequate reimbursement for these professionals is also needed.

8. Strategies should include a decrease in the use of private hospitals, in favor of public hospitals that

can take the lead in providing service to the un- and underinsured. These public hospitals are also in a prime position to conduct studies to improve services to minority populations.

9. More discussion is needed on the prevention of disabilities related to mental illness and mental health (e.g., substance abuse). Alcoholism and substance abuse compound the many other issues of social disfunction for persons with disabilities and must be addressed. One strategy might be to have personal care assistants visit the homes of persons with mental illness whenever certain symptoms occur in order to prevent further injury to those persons or their family members.

10. The importance of good coordination among agencies cannot be understated:

    - More emphasis is needed on the value of coordination at the state and local levels and on techniques for improving the efficiency of that coordination.

    - An additional strategy to improve local coordination would be to require grant applicants to demonstrate how they will work with community-based organizations to enhance local relationships.

    - The paper should call for one single federal agency to be established for addressing the issue of disability prevention. This would improve coordination significantly and reduce waste and duplication.

    - The team approach to service delivery should be promoted. All health professionals, particularly physicians, need to be trained to become team players and accept the willingness of the person with disabilities to be in control of his or her own life. Individuals should have a single point of access to these teams at the local level to provide continuity and consistency of care.

11. The need for support of families should be recognized more fully in the paper.

12. Comments concerning financing include:

    - Specific mention should be made in the paper of the special concerns of Native Americans, particularly in terms of health insurance coverage.

    - The paper should call for further exploration of alternatives for the financing of health services. The reimbursement process should be based on a wellness model of health, rather than the current sickness model. Universal access to health care is essential. Consideration should be given to testing payment schemes for prevention that are distinct from traditional health insurance packages.

    - The paper should mention the institutional bias and acute care orientation inherent in many Medicaid programs and call for appropriate corrective action. Comprehensive Medicaid reform is needed to shift the financial incentives from institutional care to individualized, flexible support systems for health promotion and maintenance.

    - The Social Security Administration is currently working to eliminate work disincentives. The paper should instead promote policies to allow disabled workers to pay insurance premiums to maintain

Medicaid or Medicare coverage while working, and to retain those benefits at no cost when not working.

- Funding should be created at the national level for high risk minority communities to design and evaluate primary disease prevention programs.

13. The paper should call for the creation of national guidelines or standards for the treatment of many chronic diseases such as coronary heart disease, chronic lung disease, and osteoporosis. These standards could be used by various third party insurers and accrediting organizations to assess quality of medical care. They should include both medical criteria and patient education. The paper should state that the quality of services should never be compromised to increase the quantity.

Education, Advocacy, Community Coalition

1. The paper should caution against promoting the use of health services unless the health system can respond appropriately to increased demand.

2. Educational interventions should strive to modify the environment (e.g., prohibit smoking in public settings) in order to make healthy lifestyle choices easier to adopt.

3. The educational system, and society as a whole, needs to support the desire of persons with disabilities to reach their full potential. The paper should go beyond prevention to suggest strategies for maintaining and increasing the abilities of persons with disabling conditions.

4. Innovative school health education curricula should focus on empowering students to make healthful lifestyle choices. True health education needs to become a national reality in primary school settings.

5. The need for training of persons with disabilities to interact more effectively with physicians and other health care professionals should be mentioned. This training should provide skills in how to ask the right questions and be assertive. Shared responsibility between persons with disabilities and health care professionals should be promoted.

6. Comments relating to professional education and training are as follows:

   - The paper should emphasize the importance of health professionals recognizing the dynamic nature of chronic conditions and the value of persons with disabilities believing in their ability to recondition themselves and improve their health status.

   - Medical school training needs a new balance between clinical/biologic issues and psychosocial issues. Stronger emphasis should be placed on one-to-one patient education, on the value of disability prevention and the importance of referrals to allied health professionals.

   - Education is needed to increase the understanding and respect between the medical community and persons with disabilities. Physicians and other health professionals often dismiss many disabilities and secondary complications as products of the aging process, rather than as conditions requiring attention and management.

- Health care professionals need early and regular exposure to persons with all types of disabilities throughout their training experience. This might be accomplished through close relationships with nearby independent living centers.

- Information on rehabilitation should be included in physician training.

7. The discussion of educating employers should be discussed in greater detail. For example, pre-employment screening programs often discriminate against and discourage those with chronic conditions (although this may change with the implementation of the Americans with Disabilities Act).

8. Public education efforts should not only use public figures as role models, but also local neighbors and peers. This would recognize the fact that most Americans will never be superstars and may be better able to identify with role models who more closely match their own socioeconomic status.

9. Persons with chronic conditions are large in number and represent a potentially strong force for restructuring the health care system. The paper should recognize this potential and encourage its mobilization.