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Health Care Reform That Works for All Americans

by Lex Frieden

Health care is a means for individuals to achieve full health and function, to participate fully in society, and to be independent. It is the means for society to reap the varied benefits for a fully functioning, healthy populace. These aims should be considered as we set about reordering health care delivery and financing.

As we engage in health care reform, our decisions should be guided by whether the proposed reforms achieve health for all of our citizens. One group in particular that will be profoundly affected by health care system changes are the more than 43 million Americans who have disabilities. This growing population -- which cuts across all lines of gender, race, and economic status -- is made up of people with varying talents, skills, and resources.

The failure of the current health care system to provide these individuals with access to appropriate health care, such as rehabilitation services, severely limits the contributions that this significant portion of the population can make to our society. As an integral part of the reform debate, it is important that we find health care solutions that will empower people with disabilities, enable them to function as independently and productively as possible, and thereby promote -- as a matter of public policy, their full participation in life and work.

Examples of failures within the current system include inadequate coverage for preventive and health maintenance services, which inevitably leads to greater costs for acute care services. A recent study conducted by The Institute for Rehabilitation and Research (TIRR) of Houston, Texas, suggests that more then 20 percent of people who are living with disabilities developed preventable health complications related to their disabilities because their health care coverage was inadequate or nonexistent.

Furthermore, some 16 percent of individuals responding to a national survey reported additional loss in function because of inadequate health care coverage for needed services. Such gaps in coverage are not means to promote full health; rather, they are the undesirable end products of efforts to control access and contain costs. While limited short-term cost savings may be realized from denying certain kinds of services, there is evidence to suggest that significantly higher costs may be the price paid over the long-term for service denials or delays.

A critical dimension of the reform debate relates to ensuring adequate and timely access to specialized providers, such as occupational therapists and other clinicians who have expertise in working with individuals with disabilities and in treating associated complications that can arise. No example is more compelling than in the case of a child with a congenital disability.

In recent hearings before the U.S. Senate Labor and Human Resources Committee, Marilyn Hogan Weisner testified on the importance of outpatient rehabilitation services to the health and well-being of Thaddeus, her nine year old son who has cerebral palsy. Ms. Weisner noted that "...without the physical, occupational and speech therapy he has received, Thad's body would be restricted by contractures; he would suffer hip and shoulder dislocations. He would require repeated painful surgeries to overcome, but never fully correct, these problems. He would have progressing scoliosis which would eventually impinge on his internal organs, causing damage.... Instead, because of physical, occupational and speech therapy...he has made tremendous progress in his development."

Because of the services provided her son, Ms. Weisner noted that "I can now anticipate the day when he will become a functioning, productive adult who can contribute to his own support, and hopefully, never live in an institution."

Another important issue raised by many of the major reform proposals in their increased reliance on managed care, through health maintenance organizations (HMOs) and similar health care delivery mechanisms. While managed care has been described by some as rationing, the best current models attempt to coordinate services, to provide better preventive care, and to contain costs.

The preeminent public policy questions which must be considered in the current debate are: Who will make critical service decisions? And, what outcomes will be deemed appropriate for what expenditures? If overall health and optimal functioning are considered the outcomes, the value of services such as rehabilitation increases. If the goal is solely to contain short-term costs, the "ends" of cost containment and access control defeat the "means" to achieve full health and lower long-term costs for health plans and for society.

If managed care is to be the predominant theme in health care reform, several safeguards are required to meet the needs of people with disabilities. To begin with, physicians' judgements about proper care must not be compromised in the drive toward cost containment. Primary care physicians should be able to refer plan participants with disabilities to physician and non-physician specialists without fear of being financially penalized or disciplined for doing so.

Mechanisms should be developed to allow people with special health care needs to secure the services of specialists who can most effectively meet their needs without unnecessary and time consuming visits to primary care providers. In cases where people with disabilities need the services of certain specialists, they should be able to select the provider of choice regardless of whether the provider is a member of a particular network or not.

In cases where specialists provide basic services to individuals with complex conditions, they should be reimbursed at primary care rates. This would prevent costly complications arising when a primary care provider, for instance, engages in unnecessary diagnostic and treatment procedures for an individual with a complicated health care condition when that individual presently only needs treatment for an unrelated minor condition.

Managed care strategies must accept and acknowledge the variety of medical and other conditions patients present while still accommodating the goals of managed care. Attention to these issues can only improve managed care's outcomes in terms of the health of all patients.

The needs of people with disabilities should be considered as a litmus test for the effectiveness of any health care reform proposal. When health care focuses on maximizing the individual's potential by insuring timely and appropriate services, health care reform will then address the issues of all Americans.

# # #

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THIS MAN HAS MOVED MOUNTAINS

MEET LEX FRIEDEN, SENIOR VICE PRESIDENT OF THE INSTITUTE FOR REHABILITATION AND RESEARCH (TIRR)

Lex Frieden grew up in a small, wheat-farming community in northwestern Oklahoma, "the perfect, homogeneous midwestern town where you went to the city twice a year to buy school clothes and only old people used wheelchairs." His mother was a homemaker, his father the civic-minded president of the local natural gas company. In 1967, Frieden was high school valedictorian, captain of the golf team, an Eagle Scout, a radio talk show host and the boy his peers voted "most likely to succeed."

Having won a President's scholarship, he enrolled in Oklahoma State University. A few days before winter break, a car in which he was riding had a head-on collision. After the impact, he found he couldn't move. In fact, he couldn't feel a thing. His neck was broken and his spinal cord seriously injured.

"A neurologist pulled my mother aside and asked, 'Do you want your son to live?' She said, 'I don't understand that question.' He said, 'Well, you know he's likely to be a vegetable. He might not ever get out of bed again.'"

Even today, some Americans have a hard time believing that disabled people can be high-functioning, highly productive members of their community. For Frieden, fighting this attitude is the toughest part of being disabled.

"The first time I experienced discrimination I was devastated. After my accident, I couldn't go back to the State University because its very old buildings didn't have elevators."

"I was shocked when despite my 4.0 average, my exceptional test scores and my superlative recommendations, a brand-new university in Tulsa turned down my application. When I called the admissions office, certain there had been a mistake, I was told my application had been denied on the basis of my disability, that I would be 'too much of an imposition on other students. What if I had to ask their help getting into the few buildings with stairs?'"

After that conversation, Frieden didn't move or speak for three days. "I was practically catatonic. I couldn't even tell my parents. But this punch in the face strengthened my resolve. A few weeks later, I enrolled in Tulsa University, where they simply scheduled classes I chose to take in buildings that were accessible."

Frieden graduated Tulsa University with a degree in psychology and got his master's in social psychology at the University of Houston. In Texas, he moved into one of America's first independent living communities. "It was the only place I could live on my own. We residents had the power to hire -- and fire -- the people who were assisting us. And we were able to build one of the first non-medical, non-patronizing models for physical assistance."

After completing additional graduate work, Frieden joined the faculty at the Baylor College

(continued)

of Medicine in Houston, where he now serves as Clinical Associate Professor. He is now the Senior Vice President of The Institute for Rehabilitation and Research (TIRR)—a comprehensive medical rehabilitation center which provides a continuum of clinical, educational and research programs relating to spinal cord and head injuries and other disabling conditions.

"One of my missions in life is to spread the word about independent living. The idea is so simple. Disabled people don't need medical professionals to pull up their pants in the morning or visiting nurses to help them sip their orange juice. But that's exactly where this overmedicalized economy has driven us. By reimbursing high-cost medical services (and refusing to pay for less costly but more critical ones) we've been forced to become the kind of people that drive health care costs up – instead of bringing them down."

"When we're well," he adds, "we need non-medical assistance – help getting dressed, eating, travelling and getting in and out of bed. When we're sick, we need the attention of rehabilitation specialists who understand our particular disabilities."

Frieden wants those who are planning the health care system of the future to understand that "a better mousetrap" already exists. It's just a matter of implementing a national system of independent living and personal assistant services.

"At first, with the Americans with Disabilities Act, people were afraid that making buildings accessible would break the bank. Of course, this didn't prove to be the case. It just made it possible for that many more Americans to go to work. Providing personal assistance and independent living centers to disabled Americans is the next logical step."

Frieden should know. He was a key player in the passage of the Americans with Disabilities Act – the most sweeping civil rights legislation since the Civil Rights Act of 1964.

In 1984, Frieden was asked to direct the National Council on the Handicapped, a newly-created, independent federal agency in Washington, D.C. He knew that Congress had given the agency a specific mandate – to prepare a report that would lay out the nation's public policy towards people with disabilities.

Frieden moved to Washington and directed the drafting of a document that became the bedrock of the Americans with Disabilities Act. In 1990, only two years after the bill was formally introduced, it was passed by Congress and signed into law by President George Bush.

"Now we must ask ourselves the same question that the neurologist asked my mother. 'Do we want to let people with head and neck and other traumatic injuries die?'"

"If we don't, it's our moral obligation to make sure they don't live the rest of their lives as vegetables – dependent on overstressed families for their care or wasting away in nursing homes. We have to give them what they need to lead productive lives."

To arrange an interview with Lex Frieden, please contact Rochelle Lefkowitz at Pro-Media, 212/245-0510.

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Addressing the Health Care Needs of People with Disabilities

Carl E. Fasser, PA-C, Quentin W. Smith, MS, Lex Frieden, MA,
Laura W. Smith, MS, and J. David Holcomb, EdD
Houston, Texas

Although health care reform is needed for many reasons, for people with disabilities, improving access to appropriate and affordable health care is critical to participation in school, work, and community activities. If reforms do not address the needs of people with disabilities and chronic illness, these people will lose opportunities. Another likely result is higher costs to society associated with increased hospitalizations and other high-cost services to address acute health problems that might have been avoided if adequate and accessible primary care services were available. PAs with advanced training in treating disabilities and promoting health care address many of the primary care needs of people with disabilities. Their efforts also strengthen arguments for continued support for training of PAs. PAs working in all practice settings, both primary care and specialties, should be sensitive to the health care needs of individuals with disabilities. However, heightening sensitivity to disability-related health care issues will require further training in the interaction between disability and health and in effective techniques for delivering health care services to people with disabilities. (J AM ACAD PHYS ASSIST 1994;7:26-32.)

Considerable attention has been focused on the inability of the current system of health care in the United States to adequately address the needs of many Americans. Indicators of the "crisis" in health care delivery include inadequate access to care, poor or unequal health status, and the high cost of medical care.[1-3] According to the Employee Benefit Research Institute, approximately 37 million Americans are medically uninsured, and 17% of the nonelderly population lacked private or public health care coverage in 1990.[4] Approximately two thirds of the uninsured were in families of full-year, steadily employed workers. When faced with inadequate or no insurance, many individuals and their families forgo medical care or opt for reduced care.[1]

Expenditures for health care have increased phenomenally during the last few decades. In 1950, the United States spent approximately $1 billion per month on health care; by 1985, the United States was spending more than $1 billion per day.[5] Expenditures for health care are expected to exceed $1 trillion in 1995.[5] In spite of all the billions spent on health care, the health status of Americans lags behind that of many other countries in areas such as infant mortality and life expectancy at birth.[6]

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The spiraling costs of health care have led third-party payers to impose limitations on coverage. To reduce risk, they have (1) increased the scope of preexisting condition exclusions, (2) raised rates, prompting many employers to reduce the number of full-time employees and increase the number of noninsured contract employees, and (3) "redlined" entire industries and occupations by judging them to be "uninsurable."[3] The extraordinary increases in health care costs over the last few decades, coupled with ever-increasing numbers of individuals—employed and unemployed—who have no health care coverage, have resulted in national health care reform becoming a priority of many policy organizations and the Clinton administration.

For some individuals, what happens with health care reform in the immediate future has implications for long-term survival. This is especially true for individuals with functional limitations resulting from chronic health conditions, traumatic injury, and congenital disorders. The complexities of many of these conditions make it essential that persons with functional disabilities have accessible, affordable health care services to maintain a reasonable quality of life in a noninstitutional setting. The current health care system does not afford access to needed services for many people, including those with disabilities. For persons with disabilities, diminished access results not only from geographic and economic barriers to service, but from physical barriers in provider settings that limit the range of services. For example, many women with physical disabilities have difficulty obtaining gynecologic and obstetric services comparable to those available to women without disabilities, because many physicians do not have accessible facilities.* Many health care providers are reluctant to make structural modifications, purchase equipment that is more accessible for people with physical disabilities, or take the extra time to accommodate the needs of persons with disabilities.

The issue of access to affordable health care services has become important to everyone. Access issues have implications for the training of health care providers. As a recent report from the US Department of Health and Human Services, Division of Medicine, stated, "Access and cost control measures will increase demands for well-trained primary care providers to serve as health educators, diagnosticians, healers, counselors, and advocates."[7]

*Nosek MA. Unpublished data from the study of psychosocial behavior of women with physical disability. Grant 1 R01 HD30166-01, National Institute of Child Health and Human Development, 1993.

THE IMPACT OF DISABILITY ON HEALTH

Approximately 36 to 43 million people in the United States have physical, mental, emotional, or sensory disabilities severe enough to interfere with their work or basic life activities.[8] For purposes of definition, basic life activities encompass the well-known activities of daily living (ADLs), the ability to eat, bathe, dress, ambulate, control excretory functions, and go outside. The instrumental activities of daily living encompass the ability to prepare meals, shop for groceries, do household chores, and handle money. Research done at the University of California in San Francisco suggests that 62 different conditions are associated with the greatest dimensions of activity limitation, work disability, and the need for assistance in basic life activities.[9] Significant among the listed conditions are multiple sclerosis, loss of limb(s), extremity paralysis caused by spinal cord injury, cerebrovascular accident, cerebral palsy, mental retardation, closed head injury, and postpolio syndrome.[9]

Along with an awareness of those persons at greatest risk of disability, planners and providers involved in the health care system reform process must understand the degrees to which persons with disabilities require assistance and the extent to which assistance needs vary with age.[10] Research addressing the relationship between these crucial dimensions indicates that the need for assistance with ADLs is hierarchically ordered (e.g., difficulty bathing usually precedes difficulty toileting), and the instrumental activities of daily living assistance needs often precede ADL assistance needs.[11] These findings suggest that a general progression exists from the more complex but less basic instrumental activities to the less complex but more basic physical activities. The demand for and frequency of assistance also appear to increase steeply with age, more than 10 times as high in the elderly as in the nonelderly population.[10]

Difficulties in addressing the health care needs of people with disabilities are further compounded by problems with making tidy categorizations of those needs. First, considerable diversity exists among the conditions that produce functional disabilities. Second, extraordinary variation exists within the presentation of the same condition, such as cystic fibrosis, in different people. Third, on the basis of the degree of severity present, the type and scope of health services needed for each individual to maintain optimal health can vary enormously.

Notwithstanding differences in impact that disability has on health, it is generally agreed that many people with disabilities have a "narrow margin of health," making them more susceptible to health

problems than are people without disabilities.[12, 13] As Batavia et al.[12] emphasize, people with disabilities are not "sick" by virtue of their physical impairments. However, people with disabilities are more susceptible to a range of health problems, including (1) respiratory problems resulting from impairment of the diaphragm and respiratory muscles, (2) urinary tract problems resulting from the loss of normal motor or sensory control of the bladder, (3) dermatologic problems resulting from a lack of tactile sensitivity, poor circulation, and diminished mobility, and (4) musculoskeletal problems resulting from contractures, osteoporosis, and impaired mobility.[12]

When these concerns are taken into consideration, many of the routine health care problems experienced by persons with disabilities are preventable if adequate and timely health care is provided either before the problem arises or during the early stages of the problem.[12, 14] The general parameters of adequate and timely health care include access to (1) prevention services, (2) early intervention by physicians and other health care practitioners who are knowledgeable about disability-related health problems, and (3) support systems required for early detection of potential health problems by the individual, the individual's personal care attendant, or a health care practitioner.[12]

Lack of education of health care providers represented a more substantial barrier to access than did physical barriers.

Many persons with disabilities, however, simply do not have access to primary health care services provided by physician or other health care generalists.[12, 13] Significant among the factors identified in 1988 by experts in health care and disability as influencing access to needed primary care services were (1) insufficient training of physician and other primary care providers in the care of persons with disabilities, (2) inadequate coordination of care for persons with disabilities throughout the health care system (including triage in primary care settings), and (3) lack of knowledge or interest among physicians about disability.[13] A somewhat surprising finding of the study was that lack of education of health care providers represented a more substantial barrier to access than did physical barriers to facilities and transportation.[13] People with disabilities are constantly faced with the tasks of locating primary care providers willing to provide care and of educating those professionals concerning the nature of their disabilities and any impacts these disabilities have on their health.[12, 14]

■ EFFECTS OF HEALTH CARE FINANCING ON ACCESS TO SERVICES

The manner in which health care services are financed also limits access for many people with disabilities. In a society in which access to quality health care services is usually contingent on the consumer's ability to pay for such services at rates set by providers, persons with disabilities are at an extraordinary disadvantage. Although most individuals rely on private health insurance, usually paid for in whole or in part through employer benefit programs, persons with disabilities are often excluded from private health insurance programs. Private health insurance carriers can limit coverage or payment of services available to persons with disabilities in at least five ways:

- Using "preexisting condition" exclusions that limit coverage for a specified period of time
- Failing to cover or limiting the coverage of specified health services or devices (such as wheelchairs and other durable medical equipment) needed by people with disabilities
- Limiting coverage to certain types of providers in selected settings such as hospitals
- Requiring that certain services be designated by a physician as "medically necessary"
- Imposing deductibles and copayments that the enrollee must pay[15-17]

The Table summarizes some of the practices in use by third-party payers to limit the availability of needed services for people with disabilities.

Imposing restrictions such as these can have a devastating impact on people with disabilities. In one of the most comprehensive publications to date on health care reform, Starr[3] summarizes the impact of restrictive coverage practices on people with disabilities.

> Health care plans can reduce their costs most easily by avoiding high-risk subscribers; thus they have an incentive to discriminate against the chronically ill and disabled and any group believed to be at high risk. To gain more favorable "risk selection," the plans may even refuse to provide benefits or special services that attract such high-cost groups as alcoholics, HIV-infected individuals, and the mentally ill. Thus, without regulation, a competitive market may well drive out services for the very people who need health care the most.

TABLE. FACTORS THAT LIMIT HEALTH CARE ACCESS TO PEOPLE WITH DISABILITIES

Limitations in insurance coverage
- Rejection for any coverage because of preexisting condition
- Exclusion of preexisting conditions from coverage
- Policy cancellation when lifetime cap is exceeded
- Waiting period for preexisting conditions of 6 months, 1 year, or indefinitely
- Group member may be subject to medical underwriting when employer switches insurers
- Group health insurance coverage is tied to a specific employer and is not "portable" to other employment or nonemployment situations
- Recision of policy because preexisting condition was not disclosed on application
- Employer may not provide any group policy for employee or dependents

Unaffordability of available health care coverage
- Lack of protection from catastrophic expenses
- Separate deductibles for different services generating higher out-of-pocket costs
- Out-of-pocket costs for uncovered services not counted toward deductible or stop-loss
- High cost of conversion from group to individual policy when insured person is forced to terminate group health insurance because of disability or chronic illness
- Premium rated up for preexisting condition
- Premium for individual or family coverage reflects insurer's own estimate of probability or risk
- "Insurability" for group insurance depends on the size of group with which one is associated, not on one's health-related needs

Inadequacy of coverage for needed services
- Limited coverage for durable medical equipment, rehabilitation therapies, drugs, disposable medical supplies, and personal assistance services
- Reimbursement for short-term care only, not ongoing maintenance needs related to health
- Reimbursement denied for covered service, which insurer decides is not "medically necessary" or from which recipient is not expected to improve
- Covered service is subject to "prior authorization" on basis of insurer's undisclosed criteria of appropriateness
- Reimbursement for covered service may be contingent on prior hospitalization or limited to delivery in a specific setting or by a specific type of provider

Griss R. Strategies for adapting the private and public health insurance systems to the health-related needs of persons with disabilities or chronic illness. Access to Health Care 1988;1(3-4):1-92.

HEALTH CARE REFORM AND THE NEEDS OF PEOPLE WITH DISABILITIES

As the preceding discussion suggests, the health care system currently in place fails to adequately address the needs of many persons with disabilities. In addition to problems of access to health care providers who have some understanding of disabilities and their impact on health, the current system limits options for obtaining primary health care services through eligibility restrictions, lack of financing, service "gatekeeping," delays and denials, and limits on benefits.[18]

Furthermore, the bias toward care of acute conditions in the present health care delivery system is harmful to people with disabilities who lack access to adequate primary care, including a comprehensive continuum of preventive, therapeutic, and support services designed to reduce the risks of acute health problems resulting in secondary disabilities.[18] The acute care focus of the current health care system has also been cited as a primary cause of the greater-than-average rate of hospitalizations reported by persons with disabilities. Some of the causes of frequent hospitalizations among persons with disabilities have been attributed to lack of (1) prevention of problems through proper nutrition, appropriate medications, and diligent self-care by the individual or persons providing personal assistance, (2) early detection of problems by the individual, persons providing personal assistance to the individual, or health care professionals, and (3) effective intervention by physicians and other health care professionals with knowledge of disability-related health problems.[12]

Dooha[18] describes a number of model programs in which nonphysician primary care practitioners enhanced the quality of care available to people with disabilities by stressing prevention, monitoring service delivery, facilitating access, and coordinating referrals to appropriate care providers. Although it seems obvious that such a service delivery scheme would enhance health care quality for anyone using it, not just people with disabilities, such services are not routinely available to many individuals through our current health care delivery system. Although for most people the lack of comprehensive, coordinated services may be inconvenient and result in somewhat higher health care costs, these shortcomings are much more than an inconvenience for people who are "medically fragile." As Dooha[18] states, denials and delays "may impede access to needed services and reduce quality of care, sometimes with dire consequences."

■ USING PAS TO MEET PRIMARY CARE NEEDS

That people with disabilities have not been well served by the current health care system has been well documented.[12-14, 18] Whether this constituency will be better served through a reformed health care system has yet to be determined. However, impending health care reform offers a window of opportunity for nonphysician providers of medical services who are willing to gain a better understanding of the health care needs of people with disabilities.

One certainty about any health care reform initiative put forward by the executive or legislative branch is that it will contain significant cost-containment measures. Cost containment should involve more effective use of nonphysician primary care providers in providing comprehensive, coordinated health care services to people with disabilities.

In its eighth report to Congress entitled *Health Personnel in the United States, 1991*, the US Department of Health and Human Services Health Resources and Services Administration's Bureau of Health Professions suggested that building a health care system that assures availability and easy access to basic primary care services necessitates the right mix of health care providers.[19] This same theme was echoed by other groups contemplating the implications of health care reform with regard to provider mix. These groups acknowledged that an important aspect of health care reform will involve developing an integrated financing and delivery system that uses a panel of providers, selected on the basis of quality and cost-management criteria, to furnish individuals with basic health care services.[2, 20, 21*] More recently, it has been stated that primary care PAs, nurse practitioners, and nurse midwives will play "increasingly important roles" in a reformed health care delivery system.[7]

The emphases on health maintenance and health promotion, which are critical in developing a service delivery system responsive to the needs of people with disabilities, lend themselves well to an expanded role for PAs. Many of the services that people with disabilities require to maintain optimal health are services that PAs are well suited to provide. These include periodic health assessments, nutritional counseling, and early treatment intervention in common health problems, such as colds, flu, and urinary tract infections. Addressing the health care needs of people with disabilities requires that the provider take the time to learn about the nature of the person's disability, the environment in which the person operates on a day-to-day basis, and the resources available to the person to address health care needs.

Early research on the roles and responsibilities of PAs demonstrated that they alter medical practice patterns in ways that may be advantageous in addressing the health care needs of people with disabilities. Studies reported that medical practices employing PAs provided 64% to 73% more direct care time, devoted more time to each patient, offered greater portions of preventive and health maintenance care, and tended to be more accessible.[22-24] When compared with physicians for selected primary health care problems, PAs provided services of equal quality.[24, 25] For preventive health care practices, PAs viewed themselves as important providers of preventive services to individuals and the communities in which they reside, perceived that health promotion can change behavior, and found patient education and counseling challenging and enjoyable.[26, 27]

Rigorous studies of PA roles, responsibilities, and practice behaviors, such as those reported in the late 1970s and early 1980s, have not recently been reported in the literature. Whether the reported amount of time PAs spend in direct care is still significantly higher than that of physicians, as reported earlier, would be important to document. Similarly, research should be undertaken on amounts and types of preventive services currently provided by PAs to determine whether the prevention orientation docu-

*Task Force on Health Care Reform. The managed competition act of 1992. Proposal of the Conservative Democratic Forum. Washington, D.C. Unpublished manuscript, 1992.

mented earlier has been sustained. Such an orientation would be consistent with the priority identified by advocates for people with disabilities for a "shift away from the current 'episodic sickness' model of health care and toward a long-term partnership . . . that focuses on achieving maximum wellness for every individual."[28]

Many of the services that persons with disabilities require . . . PAs are well suited to provide.

In addition to further research on PAs' current roles, responsibilities, and practice behaviors, responding to the needs of people with disabilities in the most effective fashion as a profession will require action on several fronts. Academic training programs for PAs, with assistance from the Association of Physician Assistant Programs, will need to incorporate appropriate didactic and clinical learning specific to the needs of people with disabilities. Such learning opportunities should address health care problems that result from functional limitations caused by congenital, traumatic, and disease-related conditions. Most important, learning experiences provided to students should involve persons with disabilities not simply as clinical subjects to be poked and prodded during clinical rounds but as lecturers and subject experts.

PA students should have a clear understanding of how the patient perceives different provider behaviors, such as exposing patients in front of groups of students or other professionals, influence the therapeutic process. Such behaviors not only rob people of their dignity, but they reinforce feelings that the individual is no longer in control of his or her body, feelings that do not hasten adjustment to disability, particularly for people who are recently disabled.

Students should also be taught to recognize the valuable learning resource that people with disabilities represent. Of necessity, many people with disabilities have developed creative solutions for addressing their own health care and related needs. Drawing on the wealth of practical, and often low cost, solutions to health care problems that people with disabilities have developed to meet their needs is an approach to health care delivery often overlooked in professional preparation. People with disabilities should be frequent visitors to the classroom rather than treated only as clinical specimens in the examining room.

Similarly, continuing education programs offered to PAs by the American Academy of Physician Assistants and by affiliated state constituent chapters should include information on the basic and specialty health care needs of persons of all ages with disabilities. Such efforts should be reinforced by journal articles on the general and specialized health care needs of persons with disabilities. A concerted effort to disseminate information on accessible and appropriate health care services for persons with disabilities would place the profession in a leadership role in health care services for people with disabilities.

CONCLUSIONS

Persons with disabilities have been referred to as "America's neglected health minority."[14] If the needs of this minority group are to be addressed effectively so that optimal health and functional capabilities can be maintained, current efforts toward health care reform must include plans to provide accessible health care services in a cost-effective manner. At least part of the approach to the provision of cost-effective and accessible services to persons with disabilities and chronic health conditions should involve more effective use of nonphysician primary care providers, such as PAs.

People with disabilities should be frequent visitors to the classroom.

With significant health care reform looming large on the national agenda, the time is right for primary care professionals to examine ways in which they can maximize their contributions to a health care system that addresses the needs of all segments of the population, including persons with disabilities and chronic health conditions. In their discussion of workforce policy, Mullen, et al.[29] refer to nonphysician providers (PAs, nurse practitioners, and certified nurse midwives) and international medical graduates as the "quiet partners" in the medical work force. While encouraging efforts to "take into account the substantial presence and contributions of these practitioners," Mullen et al. also raise the question, "Are we training too many, too few, or just enough nonphysician providers?" One factor that must be figured in the answer to this question is the role of nonphysician

providers in addressing the needs of segments of society that are currently underserved by the health care system. If a sound case can be made that PAs are prepared and willing to address the primary health care needs of people with disabilities, it would strengthen the position that support of training programs for PAs should be maintained at current levels, if not expanded. ■

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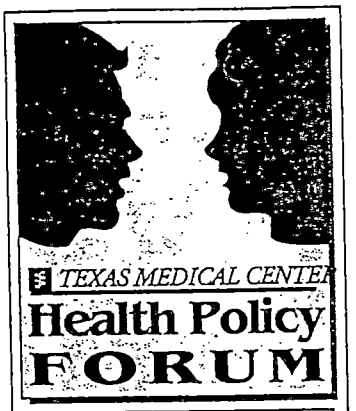

THIS MONTH'S COMMENTARY

BY LEX FRIEDEN

More people today are living with severe disabilities and chronic health conditions than ever before — due in large part to great advances in medical research and technology. The trouble is, after surviving the initial crises associated with their conditions, the vast majority of severely disabled people find that our health care system fails to meet their ongoing health care needs adequately.

The Independent Living Research Utilization Program (ILRU) at The Institute for Rehabilitation and Research recently conducted a survey of persons with disabilities who are served by independent living centers — service and advocacy programs run by and for people with disabilities — across the country. The survey results suggest that the current health care system is particularly dysfunctional for people with disabilities and those with chronic health conditions.

According to the people with disabilities responding to the survey:

- 23 percent had been denied employment because of health-related problems;
- 21 percent had chosen not to work so that they could remain eligible for public health insurance;
- 23 percent had experienced limitations in work or recreational activities as a result of the absence or inadequacy of health care;
- 21 percent had developed preventable health complications related to their disabilities because their health care coverage was inadequate or nonexistent;
- 35 percent had been unable to change jobs because of concerns about being covered for pre-existing conditions, limitations in health care coverage imposed by a new employer, and/or lack of coverage by a new employer;
- 24 percent had been denied health care services because of lack of health insurance;
- 16 percent had experienced additional functional loss because of inadequate health care coverage for needed services;
- 46 percent had been faced with not buying items that they wanted or needed in order to save money to pay for health care services; and
- 26 percent had been denied insurance coverage.

While the survey does not represent the entire spectrum of people living with disabilities, it does provide evidence that the current health care system is not working for a large portion of America's population. As we engage in the debate over national health care reform, it is obvious that there will need to be trade-offs in any plan to control costs and discourage inappropriate use of services. However, a thorough look at the fiscal impact of some of the current policies can provide equally compelling arguments for cost-effective service expansion.

We must recognize that restricting or providing only limited access to preventive and health maintenance services inevitably leads to greater costs associated with acute care services. Not covering needed prescriptions and durable medical equipment significantly increases the risks of developing more serious health problems. Not providing health care coverage for people who are engaged in part-time employment has significant physical and mental health implications and diminishes potential tax revenues. Failure to provide home-based personal assistance services or attendant care will almost certainly restrict people to their homes and beds who otherwise might be able to assume responsibilities outside their homes and even work on a full-time or part-time basis.

Limiting access to rehabilitation specialists and other clinicians who have acquired expertise in treating conditions associated with complications arising from disabilities may result in failure to address health problems in the most timely and most appropriate manner. Arbitrary restrictions on the length of stay and range or depth of services for patients in comprehensive medical rehabilitation programs may limit outcomes to the point where those who might have been able to care for themselves, engage in gainful employment, and play productive roles in family and community life, do not have the opportunity to acquire the skills needed to do so.

These issues must be considered if health care reform is to address the needs of people with disabilities who rely on accessible and high-quality health care in order to maintain physical and economic well-being, as well as long-term quality of life.

For people with disabilities, problems with the health care system are not simply related to difficulties in finding money to cover occasional episodic health problems or making choices between various health care service providers. Indeed, problems with the health care system can prevent them from working and becoming contributing, productive, self-sufficient members of society.

For people with disabilities, problems with the health care system are not simply related to difficulties in finding money to cover occasional episodic health problems or making choices between various health care service providers... The problem can prevent them from working and becoming contributing, productive, self-sufficient members of society.

As we continue to deliberate the issues surrounding health care reform, it is important that we find solutions that will empower people with disabilities and enable them to establish lives of productivity and independence.

Today, there are 43 million Americans who have disabilities. This population, which cuts across lines of gender, race and economic status, is growing. It is our responsibility, and in our national interest, to ensure accessible, appropriate and high quality health care services for all Americans, including those of us with disabilities.

(Lex Frieden is senior vice president of The Institute for Rehabilitation and Research — TIRR, clinical associate professor at Baylor College of Medicine, and program director for the Robert Wood Johnson Foundation's national program, "Improving Service Systems for People with Disabilities.")

REFLECTIONS . . .

People with Disabilities vs. a Health-Care System with Disabilities

If you break your neck in a car wreck on your way home tonight and become paralyzed, as I did 27 years ago, who will dress you, bathe you, and comb your hair after you leave the hospital?

Will it be your parents or your children? Someone from your church? A volunteer? Or can you afford to pay a nurse $10 or $15 an hour for the four to eight hours of help you will need daily?

Do you have the mistaken impression that your present health insurance will cover these costs, or that current proposals for health-care reform address this issue? Do you realize it is almost impossible to arrange volunteer assistance throughout the day and night for an extended period of time—that is, for the rest of your life!

Frankly, the likelihood you will be permanently disabled on your way home today is about equal to that of winning the state lottery. But the odds that you or a family member will need chronic care at some time are very high.

From my vantage point, the reality of the situation is both encouraging and depressing. It is encouraging to know that some people, including me, have been able to maintain a comparatively high quality of life and be productive despite severe disability and loss of function. It is also reassuring to know there are more than 200 independent-living centers across the United States run by people with disabilities who know how to organize and manage the needed services. Finally, it is nice to know we have some great models of personal-assistance service systems in states like Maine and Minnesota, and in other countries.

On the other hand, it is terribly depressing to know that the majority of health insurance plans and the current health-care-reform proposals have no provision for non-medical, in-home personal-assistance services, and that most people who can't find volunteers or can't afford to pay for help dressing and undressing, bathing, and eating, wind up living in nursing homes as public charity cases.

It seems absurd that the federal and state governments will share the cost of $30,000 or more per year to keep someone in a nursing home who would prefer to be assisted in their own home at less than half the cost to the taxpayer. Furthermore, people living in their own homes seem to be much happier and far more productive.

The bottom line is this: Millions of people with disabilities and other chronic health conditions need a little help each day with simple tasks like brushing their teeth, washing their hair, and getting a bite to eat. Yet instead of providing relatively inexpensive in-home services to these people, we wait until they get sick from poor hygiene or bad nutrition, and

then we pay in a few days what it would have cost to help them be relatively independent for several months or, in some cases, several years.

The health-care policy wizards would be wise to institute a national system of personal-assistance services and community-based supports to help control health-care costs, while at the same time improving quality of life.

Lex Frieden
Clinical Associate Professor
of Physical Medicine & Rehabilitation
and *Community Medicine*

Profile

Lex Frieden

Editor's Note: Lex Frieden is senior vice president of The Institute for Rehabilitation and Research at Texas Medical Center (TIRR) in Houston, clinical associate professor at Baylor College of Medicine, and program director for RWJF's national program, Improving Service Systems for People with Disabilities. He has devoted his entire career to helping people with disabilities overcome discrimination, live independently and improve the quality of their lives.

Since he was paralyzed from the shoulders down in a 1967 car accident, Frieden has become a leader in the movement to ensure the rights of people living with disabilities.

As executive director of the National Council on Disability from 1984 to 1989, Frieden directed the drafting of the Americans with Disabilities Act (ADA), the most sweeping anti-discrimination law since the Civil Rights Act of 1964.

ADVANCES talked to Mr. Frieden about the health care needs and concerns of people with disabilities and chronic illnesses.

ADVANCES: Is the present health care system in America adequate to meet the needs of people with disabilities?

LEX FRIEDEN: In some respects our health care system is phenomenal. More people today are living with severe disabilities and chronic health conditions than ever before. The 43 million Americans who are disabled include people with physical, sensory, cognitive and emotional impairments.

The trouble is, after one survives the initial crisis, the vast majority of severely disabled people find that they are living with a marginal quality of life. They are prevented from working and becoming contributing, productive, self-sufficient members of society. In that sense our health care system fails to meet their needs.

ADVANCES: What are some of the medical problems people with disabilities find in living independently?

LEX FRIEDEN: It's difficult, if not impossible, for people with disabilities to get basic primary care following a disability. They are often routed from one medical specialist to the next. The disability gets in the way of treating routine problems, which may be as simple as a common cold.

Another problem is a lack of community-based social and health care services, particularly personal assistance services. Many people with disabilities are forced to live in nursing homes or other institutional settings because they need assistance getting dressed and undressed. That is what the RWJF program is all about — developing and insuring the stability of a seamless system of care so that people can get the help they need in their homes and then go to work like everyone else.

ADVANCES: How do we reform the system to ensure that we have the community-based care you're talking about?

LEX FRIEDEN: Obviously, we must develop means to provide services in people's homes and in places where they live and work. This may actually be more effective and far less expensive.

I think we're on the edge of a broad-based solution in our work with independent living centers. More than 250 centers are run by people with disabilities. These community-based, consumer-run centers are successful models because their staffs can best understand clients' needs and provide the most appropriate services, which include information, skills training, peer counseling and advocacy in the community.

Our efforts should focus on developing a comprehensive, effective, community-based system of care where people can live in their own homes with assistance. This way they can enjoy a higher quality of life than they can without needed assistance, or in a nursing home or other institution.

ADVANCES: Does the recently enacted Americans with Disabilities Act offer solutions?

LEX FRIEDEN: ADA has certainly raised public consciousness and helped focus attention on the concerns and needs of people with disabilities. It also is responsible for opening doors of opportunity for many people with disabling conditions in the workplace and throughout society.

But because the ADA is primarily a civil rights act, the law doesn't ensure or require the provision of any health care or social service system that does not already exist.

Without the community-based health and supportive services I've been talking about, people with disabilities will continue to be frustrated as they search for options to be more productive and to live more independently. This contributes to chronic unemployment among the disabled adults — two-thirds of working-age people with disabilities are unemployed — and costs the government nearly $200 billion a year in support for those unable to work.

ADVANCES: How will issues affecting people with disabilities relate to issues of health care reform?

LEX FRIEDEN: As our nation continues to deliberate the issues pertaining to health care reform, it's important that we look for innovative, cost-effective solutions that will empower people with disabilities and enable them to establish lives of productivity and independence.

This population, which cuts across gender, race and economic status, is growing and aging — and will soon become more dependent on our nation's health and social services. It's our responsibility, and in our national interest, to ensure adequate services in the most appropriate settings for people who live as a result of our extraordinary health care system. ■

ADVANCES

NEWSLETTER OF THE ROBERT WOOD JOHNSON FOUNDATION

A Reprint from the Volume VII, Number 1 – The Winter 1994 Issue

Survey Finds U.S. Health Care System Not Meeting Needs Of People With Disabilities

More than two-thirds of people with disabilities who responded to a recent survey said that they were not receiving the health services needed because of limited insurance coverage, lack of access to health care providers and exclusions to health insurance based on pre-existing conditions.

The survey reflects the views of 750 people with disabilities from across the country. It was conducted by The Independent Living Research Utilization Program at The Institute for Rehabilitation and Research in Houston, Texas, the national program office for RWJF's initiative, Improving Service Systems for People with Disabilities. The program provides grants to independent living centers to streamline health, financial and supportive services for people with disabilities living in community rather than institutional settings.

Among the key findings from the survey are:

- 73 percent of those surveyed said that the high cost of treatment represents the biggest problem that they encountered in America's health care system.
- 47 percent indicated that America's health care system had gotten worse within the last five to 10 years.
- 24 percent cited inadequate personal assistance services to maintain optimal health.
- 23 percent had experienced limitations in work or recreational activities as a result of lacking or inadequate health care.
- 21 percent of respondents had developed disability-related health problems because their health care coverage was inadequate or non-existent.

Implications Of Survey

Although this survey does not represent the entire spectrum of people living with disabilities, said Lex Frieden, director for the RWJF program, it does provide evidence that the present health care system is not working for a large portion of America's population.

The findings show that in some cases inadequate health care services have resulted in additional loss of daily function necessary for people with disabilities to maintain independence, noted Frieden, who also is senior vice president for The Institute for Rehabilitation and Research.

He added that the high cost of health care services can force people with disabilities and chronic health conditions to choose between working and not working — because eligibility for public health benefits often requires recipients to have little or no income.

"The survey underscores the need for additional research on the social and economic impact of inadequate health care services for people with disabilities. These issues must be taken into consideration if health care reform is to address the needs of people who must rely on accessible and high quality health services in order to maintain a reasonable quality of life," Frieden said.

To obtain additional information on survey results, write to: ILRU, Improving Service Systems for People with Disabilities, 2323 South Shepherd Drive, Suite 1000, Houston, Texas 77019. ■

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ISSUES IN INDEPENDENT LIVING

HEALTH CARE REFORM, INDEPENDENT LIVING AND PEOPLE WITH DISABILITIES