

"Transforming Health Care Systems for the 21st Century: Issues and Opportunities for Improving Health Care for the Chronically III"

STATEMENT

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Good morning. I want to thank you for this opportunity to provide information about a few of the concerns people with chronic diseases and/or disabilities have with today's health care system.

In order to put my remarks in context, I'd like to tell you a little about the National Health Council. The Council is a nonprofit, umbrella organization whose members are more than 100 national organizations with an interest in health. Our core constituency is our patient-based groups, like the American Cancer Society, Alzheimer's Association, Arthritis Foundation, American Diabetes Association and the National Osteoporosis Foundation. The Council has over 40 of these patient organizations in its membership, representing approximately 100 million people with chronic diseases and/or disabilities. Our membership also includes health care provider groups and other organizations with an interest in health, for example, the American Association of Retired Persons, the National Hospice Organization, and the National Family Caregivers Association.

The Council has three goals:

- To promote quality health care for all people;
- To promote the importance of medical research; and,
- To promote the role of voluntary health agencies, or patient-based organizations.

Issues

Today, I want to share with you four of the primary concerns people with chronic diseases and/or disabilities have when they interact with the health care system.

First, as we all know, there really is no "system" of health care for people with chronic diseases and/or disabilities, whose health care needs are multidimensional and who require multiple services from different health care professionals and providers. According to *Webster's Dictionary*, a system is an "established, orderly way of doing something." What patients face is a confusing, and often chaotic, array of service delivery and reimbursement and coverage mechanisms. The chart (Attachment A*) attached to my remarks provides a visual representation of the complex relationships among and between various funding streams and health-related services. Trying to figure out who pays for what services and where to go to obtain needed services is an absolutely overwhelming task. There is no overall coordination of health care programs, coverage provisions, and service delivery. There is no such thing as "one-stop shopping" when it comes to putting together the package of health care services one needs.

As much as we hear about care management or case management services these days, very few persons are provided a care coordinator to assess their health care needs and service options; to determine which payment source pays for which service; to develop a single plan of care that will be followed by all health professionals interacting with the patient; to arrange the services, once elected; and, to monitor the effectiveness of the care plan developed - in short, to perform the basic services needed by persons with serious and disabling chronic conditions.

Second, there are significant problems associated with how, and how often, health care providers ask for information from individual patients. A person seeking services from a health care provider often is asked for the same information repeatedly, literally five, six, or more times, within a day. We know of examples where this has happened when an individual finds it necessary to go to the emergency room and is subsequently admitted on an inpatient basis. In addition, if a person who checks out of a hospital in the morning finds it necessary to return later the same day, he/she often finds it necessary to begin this process all over again.

The problems associated with obtaining needed patient information and sharing it appropriately within one health care setting are only magnified when one looks across health care services and provider settings.

I want to be clear that this is much more than just a nuisance for the patient and a waste of time and resources for the health care provider. It is striking evidence of the lack of coordination between providers who are caring for the same person - providers that should be sharing information and coordinating care to provide the best outcome for the whole person. We need to develop the systems to make this happen.

Third, as you know, only the poor are eligible for government funding for long-term care services. There simply is no coverage for the millions of people who may need some form of long-term care for an indefinite period of time. They must either find a way to pay for it themselves, spend down to be eligible for Medicaid, or do without. Currently, it is estimated that only between 10 and 20 percent of older adults can afford to purchase long-term care insurance.

It is also important to be aware that when we talk about long-term care for people with chronic diseases and /or disabilities, we are talking about a broad array of home and community-based services, not just the traditional institutional model. Health care services should be provided in a manner that allows a person with a chronic disease and/or disability to live as healthy and productive a life as possible, for as long as possible. Most often, this is best accomplished through an appropriate, individualized set of home and community services and support.

There are many issues associated with the financing, coordination and delivery of longterm care services. Attachment B*, which is a few pages from the Alzheimer's Association's publication, 1998 *National Public Policy Program to Conquer Alzheimer's Disease*, eloquently and succinctly describes several of the most important long-term care issues and provides other recommendations related to Medicare and Medicaid as these programs seek to appropriately meet the needs of those with chronic diseases.

A fourth issue that I want to highlight relates to the role of informal caregivers and personal assistants. For many people, their long-term care is provided by a family member with or without the help of paid assistants. These individuals are rarely viewed and treated as respected, integral members of the health care team. Yet, other than the person with the disease or disability, they often have the most intimate knowledge about the individual's health status, home environment and response to medical treatments. In addition, they often are expected to personally provide medical treatments and services, but rarely are provided the education or training to do so.

And, unfortunately, these caregivers are themselves at great risk of developing health problems as a result of their caregiving responsibilities, thus adding to the already overloaded health care needs of this country.

In addition to the four issues I have identified above, there are other serious problems with our health care system, especially as it relates to the needs of people with chronic diseases and/or disabilities. For example, Medicare is biased toward acute, institutional care and coverage is lacking for critical benefits such as drugs, eyeglasses, hearing aides, and supportive services. While I do not have time today to address these and other areas of concern, I do want to offer a few specific recommendations for improving the health care system as it relates to the issues I have raised.

Opportunities and Recommendations

1. Establish integrated, coordinated, person-centered health care across providers, services and settings.
2. Establish common, core data sets that are shared appropriately within and across providers and settings.
3. Ensure that patients are provided concise, easily understood information about their coverage.
4. Create coverage policies and financial incentives to make long-term care services more readily available and affordable for those who need them.
5. Provide recognition and reimbursement for informal caregivers as an integral part of the health care team. This should include appropriate education and training related to the medical services and treatments delivered by caregivers.
6. Provide respite care coverage for informal caregivers.
7. Expand Medicare coverage to include coverage for drugs, eyeglasses, hearing aides and supportive and other non-traditional services necessary for the care of persons with chronic diseases and/or disabilities.

Before closing, I want to note that the National Health Council and many of its member organizations believe there are some new, and very real, advantages and opportunities associated with certain aspects of the current health care system. Let me give you one example -- there is an increased ability to collect and analyze data, on an individual and aggregate basis, across components of care within many managed care organizations. This data enables us to better measure the actual health outcomes and costs associated with specific treatment regimens.

Thank you again for this opportunity to present some of the concerns and recommendations related to the health care system and its impact on the health of those with chronic diseases and/or disabilities. *
For copies of the attachments call the National Health Council at 202-785-3910