

Position Paper on Patients' Bill of Rights Legislation

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Introduction

The National Council on Disability ("NCD") is an independent federal agency that advises the President and Congress on issues affecting 54 million Americans with mental and physical disabilities. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, inclusion, and integration into all aspects of society.

NCD has been engaged in the issue of improving access to and the quality of health care for people with disabilities for many years. NCD has prepared several reports in the past that address these important issues. These reports include:

- ***Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services. March 4, 1993.*** This report identifies the major issues of access to health insurance and health-related services for people with disabilities.
- ***Making Health Care Reform Work for Americans with Disabilities. July 26, 1994.*** This report summarizes the identified health care priorities of over 130 witnesses and hundreds of participants in five "town meetings" held by NCD during March and April of 1994.
- ***Achieving Independence: The Challenge for the 21st Century. July 26, 1996.*** *Achieving Independence* is the follow-up report to NCD's 1986 report *Toward Independence*. It offers an assessment of the nation's progress in achieving equal opportunity and empowerment for people with disabilities in the last decade.
- ***From Privilege to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves. January 20, 2000.*** In this report, NCD develops 10 core recommendations for improving the care of people with psychiatric disabilities.

- ***National Disability Policy: A Progress Report. May 15, 2000.*** This report is a series of public policy recommendations designed to advance the inclusion, empowerment, and independence of people with disabilities.

As part of its health care agenda, NCD has long supported the enactment of a comprehensive and enforceable patients' bill of rights. As far back as 1996, NCD argued that "all managed care plans, including those that service only privately insured persons, should be required to meet federal standards to ensure access to specialty care, adequate grievance and appeals procedures...and equitable utilization review criteria." *Achieving Independence* (July 1996). People with disabilities and chronic illnesses are often high users of health care services and devices and, as such, are a litmus test for assessing the effectiveness of patient rights legislation. In other words, if a patient's bill of rights protects people with disabilities, it is bound to adequately protect the rights of all health care consumers.

NCD has identified the aspects of a patients' bill of rights that are most important to people with disabilities and chronic illnesses. NCD does not endorse any specific legislation. Rather, NCD supports any approach that meets the principles that are identified and described in this document. It is our hope that members of Congress and their staff, other federal and state policymakers, and people with disabilities view this position paper as a valuable tool as Congress continues to debate this important issue.

NCD Managed Care Reform Principles

Scope of Application of the Law

People with disabilities and chronic conditions have historically faced major hurdles in obtaining and maintaining private health insurance. However, NCD's 1993 report *Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services*, found that while private health insurance is difficult to obtain and keep for many in the disability community, particularly in the individual insurance market, it is still the major source of coverage for people with disabilities.

A patients' bill of rights, therefore, should cover all 161 million individuals with private health insurance in order to ensure that its protections apply to all people with disabilities. Application of the patients' bill of rights to all privately insured persons will have the added benefit of establishing a uniform set of protections on which all privately insured Americans can rely, regardless of their employer or the state laws in which they reside. This includes the 48 million Americans who receive group health coverage from their employers who self-insure as well as the additional 113 million Americans whose group or individual health coverage is subject to state law.

Timely Access to Specialty Care

The health care needs of people with disabilities and chronic conditions are best met when the focus is on maintenance of function, rather than on acute or post-episodic care. People with disabilities often require ongoing access to specialist physicians, specialty facilities, and

other specialty health care providers to maintain the functional ability required to be independent, participating members of society. In addition, the debilitating impact of many primary and secondary disabilities could be reduced or even avoided if specialty services and supports were available to people with disabilities on a routine basis.

NCD recognized in its 1996 report *Achieving Independence: The Challenge for the 21st Century* the importance of federal standards to ensure access to specialty care for people with disabilities in managed care health plans. In fact, improving access to specialty care is the highest priority for the disability community in the patients' bill of rights. NCD reiterates its belief that all patients, especially individuals with disabilities, should have timely access to specialized medical services if they need them. Health plans should ensure that the specialist is appropriate to the specific condition of the patient. If an appropriate specialist is not available within a plan's network of providers, the plan should be required to refer the patient to an appropriate specialist outside the provider network for no additional cost to the patient.

Point-of-Service Option:

NCD's 1994 report *Making Health Care Reform Work for Americans with Disabilities* detailed the challenge people with disabilities face when seeking appropriate medical care. Many adults with disabilities and parents of children with disabilities have testified that it takes them years to locate medical professionals who are competent in treating a particular disability. Any "closed panel" managed care plan should be required to offer a "point-of service option" to all enrollees, thereby permitting a person with a disability or chronic condition to access the patient's specialist of choice with reasonable cost sharing. The availability of a point-of-service option is especially important to people with disabilities and chronic illnesses, since the specialized medical care they require is often not available within the existing network of a plan's providers.

Continuity of Care:

All health plans should be required to ensure the continuity of care for patients with ongoing, chronic conditions. This can be achieved by permitting an enrollee to continue to visit his or her network of providers for a reasonable period of time after a health plan discontinues operations in a particular geographic region or disrupts its provider network in other ways. In order to minimize the impact of these disruptions, consumers should have a right to an appropriate transitional period (such as 90 days) from the date of a provider's termination from a network plan, except in cases where a provider is placing patients in harm's way through poor quality care. This transitional period should be further extended for enrollees with terminal illnesses, pregnancies, or those who are receiving institutional or inpatient care, through death, birth and discharge respectively.

Standing Referrals:

Finally, consumers with complex or chronic conditions who require frequent specialty care should have the right to "standing referrals" without having to continually return to their primary care physician to secure approval. Standing referrals can be made as part of a treatment

plan developed by the specialist, primary care provider and patient, and approved by the health plan. Timely, and in some cases, direct access to specialty care will help foster higher quality, more efficient, and cost-effective health care of people with disabilities and chronic conditions.

Timely and Accurate Comparative Information:

In a market-based health care system, reliable and useful information is critical to effective decision-making. NCD strongly believes that all health care consumers, particularly people with disabilities, must have access to accurate, easily understood information to assist them in making informed decisions about their health plans, professionals, and facilities. All consumer-directed information should be available in alternative formats that meet the accessibility and communication needs of people with disabilities so that they are able to fully participate in this decision-making process. Health plans and providers should be required to disclose whether their facilities and operations are in compliance with the Americans with Disabilities Act (ADA) of 1990.

Health plans and providers should be required to provide certain information upon enrollment and additional information upon request of the plan enrollee. Plans should provide information such as covered benefits and exclusions, lifetime and annual limitations in benefits and cost sharing requirements. Health care providers and facilities should provide information including experience rates in treating specific illnesses or injuries and accreditation status. Health care professionals should provide information including education and board-certification status. Health plans should also be required to disclose to providers and consumers drug formulary restrictions as well as exceptions when a non-formulary drug alternative is medically indicated. In addition, plans should include physicians and pharmacists in the development of drug formularies.

Right to Participate in Treatment Decisions and to Refuse Treatment:

NCD believes that all patients should be respected and afforded the opportunity to fully participate in decisions related to their health care or the care of a person under their legal guardianship. Patients should be provided with easily understood information on all appropriate treatment options and should be told about the risks and benefits of each treatment, including mental health services. All patients should also have the right to refuse treatment. Finally, health plans should establish specific policies assisting people with sensory, mental and other disabilities in order to maximize the degree to which they are active participants in the decisions related to their health care, including training health care providers to be aware of how to communicate with people with developmental, psychiatric and sensory disabilities.

Elimination of “Gag Clauses”:

NCD believes that health plans should be explicitly prohibited from restricting patient-provider communications in any manner. Providers should be allowed to inform patients of all medical options, not just the least expensive, without retribution from the plan. In addition, financial incentives designed to restrict patient-provider communications should be prohibited.

Providers should also be permitted to advocate on behalf of their patients, without retribution from the health plan.

Emergency Room Protections:

Like all health care consumers, people with disabilities and chronic illnesses are in need of emergency room services on occasion. NCD supports a patients' bill of rights that gives patients the right to visit the closest emergency room in an emergency situation, according to the "prudent layperson" standard. In other words, if a "prudent layperson" without medical training believes that he or she is experiencing an emergency medical condition and visits an emergency room, the health plan should be required to pay for this care. Prior authorization for emergency room care under the prudent layperson standard should be prohibited and the patient should pay no more for an out-of-network emergency room visit than if the emergency provider were in the plan's network. Emergency room patient protections should extend to crisis intervention and emergency mental health services provided to people with acute mental illness.

Access to Clinical Trials:

The Medicare program recently announced that it would pay for the routine costs associated with a beneficiary's participation in a clinical trial. "Routine" costs include items and services that Medicare would normally pay for, such as room and board during a hospital stay and health care services to treat the side effects and complications of the clinical trial regimen.

NCD believes that this benefit should be extended to all patients who are covered by private insurance. Patients with chronic illnesses must have access to the full range, and all phases of, federally approved clinical trials. Therefore, individuals with life-threatening or serious illnesses for which no standard treatment is available should be allowed to participate in clinical trials. Any routine patient care costs incurred in connection with participation in the clinical trial should be covered by the health plan.

Strong Grievance Procedures:

All patients, including people with disabilities, should have access to a fair and timely internal appeals process as well as an independent, unbiased external appeals mechanism to address health plan grievances and to help govern decisions about medically necessary treatments. Health plans should be held responsible for providing patients with timely, understandable notice of decisions to deny, reduce, or terminate treatment and the reasons for these decisions. All information about the grievance process should also be made available in alternative formats so that effective communication with enrollees with disabilities is ensured. NCD also believes that patients should have access to a binding independent external review process after they have exhausted the plan's internal appeals processes, except in cases of urgently needed care.

Health Plan Liability:

NCD is aware that the health plan liability issue has confounded Congress for several years and has led to an unacceptable delay in enacting a comprehensive and enforceable patients' bill of rights. On the other hand, as stated in its recent *Progress Reports*, NCD believes that without adequate remedies, there will be no meaningful patient rights. Health plans should be held accountable for the medical decisions they make, especially when those decisions harm patients or lead to the patient's death. However, the remedies within the patients' bill of rights should instill accountability in the system without leading to sharp spikes in the cost of health insurance, thereby increasing the number of uninsured Americans. Therefore, NCD will support any thoughtful, balanced approach to health plan liability that holds plans accountable for medical decisions without excessively driving up plan costs.

Patient Rights that Require Additional Attention

There are a number of issues that impact the disability community significantly but have not been included in the patient rights debate to date for a variety of reasons. While NCD is very interested in seeing a patients' bill of rights signed into law at the earliest possible opportunity, the following issues are of such great importance to the disability community that NCD will continue to work for their inclusion in the short and long term:

Benefits/Medical Necessity Definition:

One of the greatest threats to the quality of health care of people with disabilities is the restrictive trend in the breadth of most health plans' benefit packages. This trend can be seen in two primary ways: The imposition of limitations and exclusions in benefits and the way in which the term "medical necessity" is defined by the health plan. All of the major patients' rights bills completely omit this important issue. NCD believes that any definition of "medical necessity" should include the concept of not only improving, but maintaining the functional capacity of the patient, taking into account consumer choice, consumer lifestyle, and the long-term effectiveness of the intervention, service, or device under consideration.

In addition, Medicare and Medicaid provide for in-home services critical for people with disabilities, such as physical, occupational, and speech/language therapy, as well as home health aides. Such coverage is often absent or inadequate in private health insurance. Also, most private health plans do not provide coverage for assistive technologies, which are crucial in helping people with disabilities return to work, improve their functional abilities, and live more active and independent lives. Finally, private health plans should be no more restrictive of mental health benefits than they are for physical health benefits. Private health plans should include these kinds of benefits for them to be truly responsive to the needs of all people with disabilities.

Privacy and Confidentiality of Medical Records:

NCD believes that patients should be able to communicate with their health care providers in confidence and should have the confidentiality of their individually identifiable

health care information protected. Patients should have unfettered access to their own medical records and be able to request amendments to their records to correct mistakes.

ADA Application to Health Plans:

NCD believes that health plans and providers with rare exception are subject to Title III of the ADA, including the requirement to provide reasonable modifications to their policies, practices, and procedures under Title III of the ADA. In addition, private health plans and providers that receive Medicare and Medicaid funds for the treatment of these beneficiaries are required to meet the nondiscrimination provisions of the Rehabilitation Act of 1973, which apply to federal contractors and recipients of federal funds. Full implementation of these laws by health plans and providers could significantly improve access to and quality of health care for people with disabilities and chronic illnesses.