The Americans With Disabilities Act: Shattered Aspirations and New Hope

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The Americans With Disabilities Act (ADA) was a landmark civil rights law enacted in 1990. The act was critically important for enabling individuals with disabilities to access employment and thereby health care for a society in which health insurance is primarily employment-based. The ADA was designed to protect persons with disabilities from invidious discrimination and, when needed, offered reasonable accommodations and modifications to enable them to fully participate in society. The rights and futures of persons with disabilities, however, looked increasingly dim as the Supreme Court began to systematically exclude from protection those with serious diseases such as AIDS, diabetes, cancer, epilepsy, and mental illness.

To restore the ADA’s original promise, President Bush signed the ADA Amendments Act on September 25, 2008. The amendments, which became effective on January 1, 2009, directed the courts to construe the ADA “in favor of broad coverage,” thus opening the door to new opportunities for persons with disabilities. Physicians will hold a key role in implementing this new law by providing the expertise needed to prevent discrimination and enable patients to follow treatment regimens.

The ADA Amendments Act

The ADA protects individuals with a disability, who are regarded as having a disability, or who have a record of a disability. Congress defined a disability broadly as “a physical or mental impairment that substantially limits one or more major life activities.” The Supreme Court, however, twisted Congress’s intent by strictly interpreting the law “to create a demanding standard for qualifying as disabled.” The judiciary chipped away at the ADA from every angle.

Substantial Limitation. To constitute a disability, an impairment must substantially limit one or more major life activities. The Supreme Court radically redefined “substantially limited” to mean “prevents or severely restricts” a major life activity. The court similarly redefined “major life activity” to mean an activity “of central importance to most people’s daily lives.” The results were absurd. A federal appellate court ruled that a man diagnosed with “mental retardation” did not have a “disability” because he was not substantially limited in thinking or communicating and because thinking and communicating might not be major life activities. With the ADA Amendments Act, Congress specifically repudiated the courts’ definition of substantial limitation and reinstated the ADA’s “broad coverage.”

Major Life Activity. The ADA did not expressly define the term major life activity, and the Supreme Court construed it narrowly to those activities that are of “central importance to most people’s daily lives.” Rejecting the court’s “demanding standard,” the amendments create a nonexhaustive list of major life activities, including performing manual tasks, standing, and concentrating, as well as “the operation of a major bodily function,” such as immune, neurological, and endocrine function and normal cell growth. By including bodily functions, the act ensures that individuals whose conditions are well managed or in remission are again covered. This way, the focus is on the health condition, not what the person can and cannot do—for example, a cancer patient who is in remission still has abnormal cell growth.

Mitigating Measures. The Supreme Court ruled that mitigating measures, such as medication or a medical device, must be considered when determining whether the person has a disability. Lower courts followed this guidance with disastrous results. For example, one federal court upheld the termination of an employee who had a seizure at work, ruling that, because he was able to take medication that lessened the frequency of his seizures to one seizure per week, he did not have a disability. Many individuals with other equally serious health conditions found that adequately managing their condition deprived them of protection even in the face of blatant discrimination. The amendments expressly overturn this judicial precedent by forbidding consideration of “the ameliorative effects of mitigating measures” when determining whether someone meets the definition of disability. The mitigating measures that cannot be considered range widely from medications to assistive technology to learned behavior modifications.

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Conditions in Remission or Episodic. Many courts held that conditions that only manifest periodically or can go into remission such as epilepsy, depression, multiple sclerosis, and cancer were not covered. The amendments provide that an “impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active”—for example, whether a person with epilepsy is substantially limited during a seizure.8

“Regarded as” Disability. The ADA’s “regarded as” provision was designed to remedy discrimination due to misperceptions and irrational fears about disability. However, the courts excessively focused on whether, in the discriminator’s mind, the person was substantially limited in a major life activity, rather than focusing on the discrimination itself.3 This defeated Congress’ attempt to shield individuals from mistreatment due to a perceived disability—the most irrational kind of discrimination. Congress refocused the law on unfounded fears and stereotypes by breathing new life into the “regarded as” prong of the law. Accordingly, a claim is valid once an individual establishes that he or she was discriminated against because of a mental or physical impairment (whether or not the impairment even exists). There is no need to show substantial limitation on a major life activity, only that the impairment is neither minor nor expected to last less than 6 months. However, an individual who brings a claim solely under this part of the law is not entitled to any modifications or accommodations.

The sum total of these improvements is to ensure robust protection of individuals who experience disability discrimination. Rather than focusing excessively on whether a person is disabled enough to qualify for protection, the courts will now focus on whether the person was treated unfairly because of a serious injury or disease.

The Physician’s Role

The courts had placed physicians in the unenviable position of having to show what a patient was unable to do (that he or she was disabled), and then reverse course completely to extensively document that the patient could safely and effectively perform the job in question. That is an unacceptable position in which to place trained health care professionals.

Under the new act, physicians will continue to be asked to provide expertise about whether an individual is able to safely and effectively perform a job, as well as whether an individual needs modifications and accommodations at school, work, and elsewhere. Such determinations may arise in the course of treating patients or when acting as an expert witness. However, the physician’s first responsibility may still be to help the patient establish coverage under the law, which will now be easier.

In the past, medical documentation that failed to emphasize patients’ limitations undermined their disability discrimination claims. Some employers went so far as to explicitly ask physicians: “Is the patient substantially limited in a major life activity?” Physicians, reasonably thinking the question related to whether the patient could do the job, have answered in the negative and employers have used this response as evidence that the person is not covered by the ADA.

Physicians faced an especially delicate situation when an employer with unfounded safety concerns asked the treating physician for assurance that the employee could safely perform the job. Here lurked a pitfall: physicians who believed the person could safely perform the job often thought that the wisest course of action was to suggest that the patient’s health condition was minor, inadvertently blocking the patient’s disability law coverage.

The ADA Amendments Act expands the conception of disability, allowing physicians to exercise their clinical judgment. When physicians describe the condition in clear language, employers and courts will understand that individuals with diseases such as epilepsy, AIDS, and diabetes meet the definition of disability. For example, the physician can document how the condition limits neurological, immune system, or endocrine function. The physician can also explain how, without medication or while the condition is active, patients have substantial limitations in major life activities such as thinking, eating, and caring for themselves. Now, physicians can use medical terminology and play a vital role in safeguarding their patients’ rights.

Access to Health Care

Affording more effective protection against disability discrimination will lead to improved prevention and treatment. Because 60% of US residents younger than 65 years receive health insurance through employment,9 workplace discrimination deprives many individuals of effective access to health care. Persons with disabilities often require regular management, so their condition does not deteriorate, and they can function in all aspects of their lives. If they are wrongfully excluded from employment, persons with disabilities (and their families) will have difficulty receiving adequate prevention and treatment services.10

Discrimination can also deprive individuals of the means to adhere to prescribed treatment. Prior to the ADA Amendments Act, many individuals were told that they were not entitled to accommodations because they did not have a disability. The changes should discourage discrimination and give patients confidence to follow their physicians’ recommendations with the knowledge that federal law will protect them. Thus, patients will be better able to maintain treatment and avoid the complications of chronic diseases. For example, a factory worker with diabetes will now be able to have short breaks needed to check blood glucose levels and administer insulin at work.

The ADA Amendments Act will provide persons with disabilities new opportunities to work productively, maintain health insurance, and manage their health conditions effectively. The new law will allow physicians and patients...
to meet the dual goals of advancing health and making the United States a fairer place for people with disabilities.

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The Other Medical Home

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At the signing of the Medicare bill in 1965, President Lyndon B. Johnson remarked that the American tradition of helping those in despair was at the core of the law. He said, “It directs us never to ignore or to spurn those who suffer untended in a land that is bursting with abundance.” Today, Medicare’s potential for mitigating untended morbidity and mortality remains unmet. The prevailing public policy discussion is that Medicare is too costly and the anticipated increase in spending is unsustainable. Despite high Medicare expenses, older adults with serious chronic illness are at high risk for mortality, functional limitations, poor quality of life, high outof-pocket costs, and often report dissatisfaction with their care and barriers to adequate care. For the most ill and costly beneficiaries, physical illness and mental health problems are frequently compounded by the burden placed on a family caregiver, a “hidden patient” whose physical and emotional needs often remain unnoticed.

The Medicare Payment Advisory Commission (MedPAC) recently provided a set of recommendations for Medicare payment reforms. A key piece of this reform agenda is pilot testing a payment for a “Medical Home,” a concept that creates a way for primary care clinicians to receive payment for added care coordination, care integration, quality improvement, and education activities for patients with chronic diseases. The extra payments would be accompanied by added requirements and accountability for outcomes.

However, the Medical Home initiative, as currently articulated, ironically fails to emphasize the complex chronically ill patient’s actual home. This represents a failure to recognize the profile of the highest-risk beneficiaries driving much of the high Medicare costs—that is those with 4 or more chronic conditions and activity limitations whose homes and bodies are filled with the latest equipment, devices, and drugs, but often without the accessible, personal, holistic, and integrated care they need to take advantage of these interventions in ways that improve their overall well-being. These highly vulnerable Medicare beneficiaries often cannot access office-based medical practices because of their functional limitations. Even if these patients could readily get there, many physician practices are high volume and not well positioned to deliver or coordinate the type of time-intensive multidisciplinary care that can improve outcomes for these patients. This shortcoming more reflects a financing system that undervalues generalist physicians and other primary care clinicians than a failure of the physicians and practices themselves. The proposed pilot program does not go far enough to change this.

The Medical Home initiative and projects under way seem designed to meet the needs of mobile patients earlier in the course of chronic illness who need appropriate chronic disease care and self-management support to prevent debilitating sequelae. There is no clear emphasis on asking these practices to find the highly vulnerable, functionally limited patients who are driving most of the Medicare expenses. These patients are more likely to be found transitioning between hospitals, nursing facilities, and home. Another limitation of MedPAC’s proposal for meeting the needs of older adults with complex chronic illness is that there is no attempt to reform the narrow, disease-based evaluation and management visit to ensure that patients have an assessment of their comorbidities, “geriatric syndromes,” functional status, prognosis, psychological condition, and social circumstances.

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