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## SYMPOSIUM: BARRIERS TO ACCESS TO HEALTH CARE -- Introduction: Are the Walls Tumbling Down? Hardly. Are the Sands Shifting? Surely.

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# SYMPOSIUM

## BARRIERS TO ACCESS TO HEALTH CARE

**INTRODUCTION: ARE THE WALLS TUMBLING DOWN? HARDLY. ARE THE SANDS SHIFTING? SURELY.**

**EVERYONE HAS THE RIGHT** to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.<sup>1</sup>

The United States has not yet recognized the right to an adequate health-supporting standard of living or the right to medical care or "to security in the event of . . . disability," as described in the 1948 United Nations *Universal Declaration of Human Rights*.<sup>2</sup> Nor has the U.S. met the United Nations standard in terms of health and disability.

The articles in this Symposium describe some of the barriers to people gaining health care access. The issue would have to be a multi-volume treatise if it tried to identify and analyze all of the obstacles to health care in the United States. The authors in this issue are practitioners (legal and medical), community activists and law professors. Some fit into two or three of the categories. They all have experience with the issues they de-

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<sup>1</sup> HUMAN RIGHTS: A COMPILATION OF INTERNATIONAL INSTRUMENTS at 3 Art.25, U.N. Doc. ST/HR/1/Rev. 1, U.N. Sales No. E.78.XIV.2 (3d ed. 1978) (emphasis added).

<sup>2</sup> *Id.*

scribe. Because of their experiences, they bring perspectives that are fresh. They describe ongoing processes. They describe the current state of the law and anticipated directions for the law.

“The Law Is All Over.”

All of the barriers to health care are described in a legal context. The reason is obvious. As a client in Austin Sarat’s study observed: “The law is all over.”<sup>3</sup> And the law is ever changing.

Laws passed by federal and state legislatures are addressed specifically to the provision of health care. They set up criteria for eligibility for access to some health care and the extent of services that may or must be provided. They prescribe the conditions under which services may be available and the finances for providing health care in some circumstances. Other more general laws—designed to regulate the economy, credit, and bankruptcy—impact on people’s choices and ability to obtain health care.

Courts have been asked to interpret statutes. They have ordered remedies that are often far-reaching. Some have occasionally determined that they have no role in interpreting or enforcing law such as the Medicaid statute. In addition, the law is with us as governmental and non-governmental agencies and organizations strive to develop systems to make health care available.

Financial Barriers: Medicaid

The articles in this Symposium address various barriers—and means to avoid the barriers—to access to health care. We can all describe one major barrier. It is financial. If one does not have health insurance, one is much less likely to obtain health care. Moreover, the likelihood of receiving adequate and medically necessary health care is extremely low—unless one is financially independent.

Medicaid was established in 1965 to provide access to health care for some poor people in families with children or for those who are disabled or aged. It has provided great assistance

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<sup>3</sup> Austin Sarat, “. . . *The Law Is All Over*”: *Power, Resistance and the Legal Consciousness of the Welfare Poor*, 2 *YALE J.L. & HUMAN.* 343, 343 (1990).

but has, as Jane Perkins's article describes, left serious gaps. Welfare reform, community and faith based services, and other changes over the past decade have caused changes in the ways that social services (including health care) happen.

One of the unfortunate results of cutting families off cash assistance has been the erroneous and illegal termination of people on Medicaid rolls. Welfare reform "de-linked" Medicaid from cash assistance. People lost cash assistance because they obtained jobs that replaced the grants or because they were sanctioned for failing to follow the new rules. Most jobs failed to bring families out of poverty and generally did not provide medical insurance benefits. Whether people lost cash benefits because of sanctions or because they obtained jobs, many of them lost Medicaid improperly.

When they lost cash benefits, minimal as they may have been, families also often lost Medicaid, the publicly financed health care for poor families. In Ohio, for example, 160,000 people were improperly cut off Medicaid, often when they were cut off cash assistance. The State agreed to reinstate those people who requested reinstatement. Legal services programs across the state worked to assist the reinstatement process. Students at Case Western Reserve University Law School mobilized to provide assistance during the reinstatement process, publicizing the restoration by the State and providing a phone hotline and walk-in service almost forty hours a week for ten weeks. They hoped to assist at least some of those who were wrongfully terminated—25,000 in the county where the law school is located. They spoke to some, helped some to reapply, and distributed application forms and information to other social service agencies. Unfortunately, only a small fraction of those whom the State identified as improperly terminated were reinstated after nine months of work by the advocates. Small errors can cause big changes and harms.

The result is that the more things change, the more things remain the same. There are still many, many people who are poor or "medically indigent." Many of them are not eligible for publicly subsidized health insurance. Many of those who are eligible are not receiving publicly subsidized health insurance. Many of those who are receiving Medicaid are not receiving the services that Medicaid is supposed to be providing. Many people are still trying to expand access to health care to poor and medically indigent people by improving the scope and imple-

mentation of Medicaid and other health insurance. And others are looking to contract the availability of Medicaid by limiting the people who are eligible, decreasing the services provided and increasing the cost of the insurance and services.

#### Financial Barriers: Medical Debt

People who are not financially eligible for full coverage by publicly financed health insurance have serious barriers to health care. Trey Daly, Lisa Oblak, Robert Seifer and Kimberly Shellenberger describe many of the problems that people with medical debt have. A high percentage of personal bankruptcies are related to medical debt. It is certainly not sufficient to say that health care is a commodity that you decide whether you need and that you forego if you cannot pay for it. Certainly the impact of medical debt for uninsured or under-insured people is that they think twice before they try to get medically necessary care again. Consequently, their health status suffers.

#### Unique Barriers for People With Disabilities

People with mental disabilities have unique barriers to obtaining appropriate medical treatment for their disabilities. Joan O'Sullivan and Breck Borchering describe the difficulties in obtaining treatment, particularly in Maryland. Before giving treatment for a mental disorder, the provider must obtain informed consent. State law forbids surrogate decisionmakers. But how is an untreated person with a mental disorder able to give informed consent? And how do you decide to continue treatment when there is no evidence that there ever was informed consent? And how do you decide to stop treatment, knowing that stopping medication may have disastrous effects? Why is the law as it is? What protections are intended and necessary? What changes to the law should be made?

The Americans with Disabilities Act protects people with disabilities. *Olmstead v. L.C.*<sup>4</sup> is a 1999 groundbreaking Supreme Court decision that basically requires that people with disabilities receive health services in the community when possible. The previous public spending for people with disabilities is being realigned to include many more community-based services. The courts have lowered a barrier to less restrictive set-

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<sup>4</sup> 527 U.S. 581 (1999).

tings for health care treatment of people with disabilities. The states are taking seriously the statute-based court mandates. Access to appropriate health services is increasing with the enforcement of the ADA through the courts, according to the article by Sara Rosenbaum, Joel Teitelbaum and Alexandra Stewart. The process of change continues.

Waiting lists for community services are also being challenged. Margaret Feltz describes court challenges to Medicaid waiting lists and their context with *Olmstead* litigation. Litigation has provided, at the least, a catalyst for change. It has also shaped the priorities for changes. As a two-edged sword, it can bring attention to important barriers to service. It can also mandate the use of state funds to the value of some and possible detriment of others.

#### The Courts: Access or Barrier

The courts are being asked to enforce the federal requirements of the scope of Medicaid. Erwin Chemerinsky's article explains why the federal courts can and must continue to require the States to provide the services that Medicaid mandates. The issue has become complicated by various views of federalism. The history of a recent federal district court case, *Westside Mothers v. Haveman*,<sup>5</sup> puts the issue in perspective—contrasting the history of courts enforcing Medicaid with the current development of the limits on the federal courts and Congress. The *Westside Mothers* case was filed in Michigan, with the plaintiffs asking the court to require the state agency that administers Medicaid to provide early periodic screening, diagnosis and treatment for young children as Federal Medicaid law mandates. The trial court decided for various reasons that it could not enforce congressional mandates of particular kinds of services against the State of Michigan. Erwin Chemerinsky and Jane Perkins have both crafted briefs that are with the Sixth Circuit Court of Appeals.

The outcome, if it supports the trial court, may have profound effects on the coverage that Medicaid provides if States choose not to comply with the federal standards. It would also overturn decades of availability of court redress for poor people.

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<sup>5</sup> 133 F. Supp. 2d 549 (E.D. Mich. 2001).

On the other hand, the courts have been open to requiring health and habilitation services in the least restrictive environment feasible and as promptly as possible, as noted in other articles by Rosenbaum, Teitelbaum and Stewart and by Feltz. These court decisions have continued the tradition of recognizing—implicitly or explicitly—that a right without a remedy is no right.

### Change Is Inevitable

Changes are happening. As Perkins' article explains, more people are eligible for Medicaid. Some Medicaid services may no longer be mandated. "Mandates" may no longer be enforceable. Finances still affect health care decisions and health care costs still affect financial decisions of low-income people, as Daly and colleagues point out. Other publicly financed services are expanding and becoming more appropriate.

States are trying to combine publicly financed and employer-based health insurance to fill some of the gaps, according to Louise Trubek. Trubek's article discusses reform, using initiatives such as Wisconsin's BagderCare program as an example. Medical services are not now but may become more available, while preserving protections against inappropriate or nonconsensual treatment, as described by O'Sullivan and Borcharding. The courts have historically enforced Medicaid requirements against the states, as shown by Feltz; a change in that history may be an aberration or a trend, as examined by Chemerinsky. And as discussed by Rosenbaum and colleagues, the courts are enforcing the ADA to increase access to health services in the community.

The authors raise cutting-edge issues. Barriers to health care are everywhere for people with low income and with disabilities. The law is also everywhere. It can work for these populations or against them. The changes continue. The U.N. human right is still unrealized, but that can change too.

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