



A Consumer Bill of Rights

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A Consumer Bill of Rights

While we have been caught up this summer in the tug-of-war that is the federal budget process, another group of influentials has been gearing up for an equally formidable task. The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry consists of thirty-two commissioners, and as of September 10, the commission had met four times. My best guess is that most people have never heard of this group, let alone what it is trying to accomplish by the end of 1997.

According to *Commission Connection*, a joint publication of the Health Care Quality Alliance and the National Health Council, President Clinton has requested that the commission develop a "Consumer Bill of Rights and Responsibilities" by this fall. At its September meeting, the commission focused on reviewing the work of its Subcommittee on Consumer Rights, Protections, and Responsibilities. This subcommittee has outlined ten issue areas in its work plan: Access, Choice, Benefits, Information, Treatment Decisions, Grievances and Appeals, Nondiscrimination and Respect, Confidentiality and Privacy, Responsibilities, and Consumer Assistance. Once the subcommittee members take testimony and review background papers, a draft will be prepared for the "Bill of Rights" that states the right, provides the rationale for the right, and discusses the implications.

Thus far, according to the *Commission Connection*, the subcommittee has reviewed chapters on Non-Discrimination and Respect, Consumer Grievances and Appeals, the Right to Information, and the

Right to Consumer Choice. Not surprisingly, the issue of cost often dominates the work of the subcommittee; some members are taking the position that rights should be offered only "if they bring no additional cost to the system or otherwise interfere with the industry status quo." I am probably not the first to be thankful that our nation's Founding Fathers did not apply this same litmus test in drafting the original Bill of Rights.

Members of the Health Care Quality Alliance have testified that they are concerned about the tone and directions of the subcommittee's deliberations. They stated that "although costs may impact the mechanisms or pace of implementation of the proposed rights, costs should not deter the actual expression of core values." In addition, they testified that they are concerned that the purchaser and not the patient has been the focus of the subcommittee.

The *Commission Connection* reports that increasingly there is confusion among the commissioners over their primary mission and goal. That is, should the commission make recommendations that are practical and feasible with little additional costs in light of the current health care climate—or should it create a vision of what the nation should strive to ideally achieve in our health care delivery system?

Secretary of Health and Human Services Donna Shalala, one of the commission's co-chairs, has stated to the commission that the Bill of Rights should be pragmatic because "it's going to end up in legislation. The President wanted us to push against the sides of the envelope." However, the commission is finding that pushing against the side of a "business" envelope results in paper cuts.

To illustrate the strength and influence of the status quo segment of the commission, one need only

look at the "The Right to Consumer Choice" chapter discussions. Again, as described in *Commission Connection*, it was proposed that a statement regarding access to specialists, an extremely important issue to cancer patients, originally read, "Consumers with chronic, disabling, or terminal conditions who require frequent specialty care should have direct and ongoing access to a qualified specialist of their choice or authorization for an adequate number of direct access visits to cover a six-month period." However, suggested changes have called for the removal of the word chronic to be replaced by "catastrophic" and the deletion of the phrase "of their choice or authorization for." So, if amended as suggested, a fairly strong right to specialists would read, "Consumers with catastrophic, disabling, or terminal conditions who require frequent specialty care should have direct and ongoing access to a qualified specialist for an adequate number of direct access visits to cover a six-month period." The determination of "terminal," "qualified," and who would require "frequent" specialty care could well change dramatically for cancer patients who would no longer have assurances to see their own oncologists.

While this information comes from "biased" sources—the Health Care Quality Alliance and the National Health Council—it seems abundantly clear that patients and providers of oncology care need to voice their concern and get involved. In October ACCC hosted a meeting entitled "Partnerships in Patient Advocacy" near Washington, D.C. Ironically, the Consumer Rights Subcommittee met the same day in Washington at the HHS building conference room. The commission does have a website where dates and agendas are provided at <http://hcqualitycommission.gov>. ■

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