An Insider’s Perspective On The Near-Death Experience Of AHCPR

A former agency administrator fills in some details of the struggles of health services research in the mid-1990s.

by Clifton R. Gaus

ABSTRACT: The story of AHCPR’s struggle with Congress to remain a federal agency is an example of the longer struggle health services research (HSR) has had to hold a priority in the federal budget. But from another perspective, the growth of HSR has been substantial, albeit an up-and-down experience. Its survival during the turbulent years of 1995–1996 is attributed to a fundamental restructuring of its program priorities and building a new base of support from major health care associations and leaders. A fortunate sequence of events also contributed to the reversal of what could have been a cataclysmic occurrence for the field of HSR.

I first commend Brad Gray and his colleagues for having carefully researched the turbulent and tortured history of health services research (HSR) and the Agency for Health Care Policy and Research (AHCPR). As they correctly point out, this history is but a small window to the longer struggle of a new field of intellectual inquiry to attain fiscal and scientific legitimacy within the federal government. In this short commentary I do not review the fine points they make about the influence of adding outcomes research to the federal HSR agenda or the reasons biomedical research fares so well in the federal budget. To someone now clocking his thirty-fifth year in the field of health services research and policy and two different stints in the federal HSR bureaucracy, it remains a befuddlement and frustration of enormous scale to see our bigger brother, biomedical research, grow so large while HSR often struggles, especially now, to barely keep pace with inflation in the federal budget.

On the other hand, maybe the standard of comparison is too high. While one can argue that the relative size of spending on HSR versus biomedical research is too small given the opportunities to improve quality, save lives, and lower health care spending, one cannot dispute the fact that growth in HSR spending from 1980 to 2000 was significant. In fact, the spending of AHCPR and its predecessor agency, NCHSR, grew almost 800 percent in those two decades, at a time when private-sector foundation spending was also growing rapidly. My half-empty cup says that we have done well despite the vagaries of power and politics. The scary part is that it could have easily gone the other way. If the critics of HSR in the 94th Congress had prevailed, we might now be comparing the 1980 budget of $25 million to $0 in 2000. The determination of both

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the agency staff and its many private-sector allies and a little bit of luck made the difference.

Determinative agency staff and allies. As I made the rounds during those days, I used a quote that seemed to characterize the determination and seemed to rally the allies: “As Jesse James once said, there is nothing like a hanging to concentrate the mind!” In fact, Jesse James probably never said that and anyway died from a gunshot for the bounty on his head. What was correct was that the agency was about to be hanged and needed rescue. As Gray and colleagues point out so well, it had too few friends in the right circles, was vulnerable to criticisms of waste and inefficiency, was identified with partisan politics, and had committed enemies.

All of these were true to some extent. The agency had clearly lost its champions in Congress through retirements and change of control. All federal agencies waste money at times. Exposing this is not hard; getting someone to listen is actually harder. Partisan politics is a half-full, half-empty cup. The agency did leave itself exposed by the extra effort it made to have its data and analyses used by the Clinton health reform team, but having watched that process myself, I can say without a doubt that the HCFA Office of the Actuary was more influential, and both it and AHCPR were unbiased in their analyses. My appointment to lead the agency could be perceived as political, but what government agency head is not appointed by the political party in the White House? As far as enemies go, AHCPR had many among the back surgeons who were more than miffed by the guideline saying that they cut too often, sometimes hurting patients, and that “watchful waiting” was often better than surgery. That hurt their pocketbooks and professional integrity; no wonder they wanted AHCPR put out of existence. They, like other critics, enjoyed the “piling on” process and gave us a formidable challenge from clinical circles.

For the first few months of being on the congressional hit list, we tried to deny all accusations and to figure out how it happened and who did it, so that we could “confront the enemy.” It turned out that a simpler and more enduring strategy would work. This was, first, to refocus the agenda on priorities that fit the times and, second, to build a network of influential organizations around that agenda. That meant listening to the users of our research to set priorities—not those doing the research.

My most memorable experience in this regard was when I started calling insurers, hospitals, and clinical leaders about the clinical practice guidelines. Almost unanimously they said, we don’t use your guidelines per se, but the synthesis of science you base them on is invaluable to us in writing our own guidelines. What a revelation! Thus was born the whole idea of evidence-based practice centers and the abandonment of the federal guideline process. Creation of the National Guidelines Clearinghouse (www.guidelines.gov) brought the private-sector guidelines into the sunshine and gave the agency prominence in the dissemination process.

We also listened to consumers and the need for better quality information (the Consumer Assessment of Health Plans, or CAHPS), and we partnered with many clinical leaders to develop better quality measures (the National Quality Measures Clearinghouse). Finally, we stopped openly advocating for ourselves and let others do it for us. While I would have loved to openly debate Rep. Sam Johnson (a big critic) on television, I would have appeared self-serving. Why not ask one of the most prominent medical practitioners to make our case for us, we thought. Doug Henley from the American Academy of Family Physicians agreed, and the strategy worked marvelously.

As a result of rebuilding the agenda, almost
every major health professional and trade organization came to the agency's support. Interest groups that were usually on opposing sides on every issue seemed to agree the agency should survive. Some major ones, such as HIAA, AMA, AAMC, and AAHP, actually put their network of lobbyists to work garnering votes in Congress. This also helped several already sympathetic staff to work the members and conceptualize the political deal that would save the agency.

- **A little bit of luck.** As to luck, several things happened. First, as the committees in the House of Representatives changed hands in the 94th Congress, several HSR-sympathetic staff members took influential leadership positions with the Ways and Means and Appropriations Committees. Second, at about the same time we were seeking a compromise on the budget to save the agency, the extremism of the Contract with America was causing angst in the moderate circles of the House leadership, and “punishing” versus “hanging” seemed reasonable. Third, there appeared a need for additional education appropriation dollars, and Congressmen Obey, Thomas, and Porter were key to the House leadership's getting those dollars; this gave them a negotiating chit over the AHCPR budget. They used the chit to force the House to accede to whatever the Senate funding number was for AHCPR instead of splitting the difference, which they typically did. Since we didn't know what the Senate number would be, it was a great gamble and hard to swallow, but the result was a budget of $125 million—a painful cut but not crippling—and we had paid our dues.

The last stroke of luck for the agency occurred after all the dust had settled and it was time to rebuild and grow again. I was ready for new challenges, and I recognized from the two years of political wars that the agency needed a respected clinician to lead the next phase. I had been friends with John Eisenberg, chairman of medicine at Georgetown Medical School, for many years, and I greatly admired his vision and leadership. As it turned out, this was a time of change for him, too, and one day in casual conversation I learned something that would seal the deal. The next day I told Donna Shalala, secretary of health and human services, of my plans to leave the agency once a successor was found. She asked who I thought that successor should be; I replied that it was someone she had great admiration for: her personal physician, John Eisenberg. The rest was paperwork.

Now, almost eight years later, after the tragic passing of Eisenberg following four fabulous years of agency rebuilding, the new agency (AHRQ) will likely have a 2004 budget in excess of $300 million, significantly up from a low point of $25 million in 1980 and the hiccup in 1996 of $125 million. On 16 June 2003 the agency moves into a new headquarters building named after Dr. John M. Eisenberg. The future of the agency looks good.