

NINTH ANNUAL HERBERT LOURIE MEMORIAL
LECTURE ON HEALTH POLICY

**Patients as Consumers: Making
the Health Care System
Our Own**

David J. Lansky

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Policy Brief

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I ask you to think about our health care system. Think beyond the issues that are in front of us today: the anxiety we have about managed care, obtaining our own health care and paying for it, the survival of Medicare, and the unpredictable impact of government regulations. Think about our health, what we want from our health care system, what we're spending all this money for, and what we care about for ourselves and for our families.

The challenge we face in the next five, ten, or fifteen years is to place the American health care system under the control of the people who pay for it, who receive the care, and who care the most about the health of the people in our communities.

Becoming Informed Consumers

In his 1996 Lourie Lecture, David Lawrence reviewed the issues facing managed care and told us that we have limited tools with which to measure the quality of health care. While measurement systems are getting better, it will be some time before we have the kind of data that will allow us to determine what works, for which populations, and under what circumstances.¹

Yet this demand for better information about what works in medicine is not new. Managed care executives like Dr. Lawrence want information in order to manage and improve large, complex health systems. But well before our contemporary policy debates, American health professionals sought to understand and

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disseminate information about what works and where patients could obtain the best care.

Information from Health Care Providers

In 1754 the Board of Managers of the first colonial hospital, Pennsylvania Hospital, published a chart summarizing the status of patients who had been admitted and discharged.² On the left-hand side were listed the diagnoses of the day: flux, wounds, palsy, dropsy, emphysema, harelip, and lunacy. Across the top were printed the status of patients at the time of discharge from the hospital: “relieved of symptoms,” “discharged with irregular behavior,” “discharged incurable,” “taken away by friends” or “dead.” Nearly 250 years ago an American hospital routinely tabulated the outcomes of its patients in terms that we easily recognize as relevant for us today: symptoms, cure, death.

Ernest Codman, a surgeon at Massachusetts General Hospital in the early 1900’s, developed the “end result” system, which took the Pennsylvania Hospital model a step further. His staff tracked patients, through their physicians, after discharge from the hospital to determine the long-term results of medical treatment. He identified the reasons for less than optimal outcomes by such categories as “errors due to lack of technical knowledge or skill,” “lack of surgical judgment,” “lack of care or equipment,” or “lack of diagnostic skill”; the patient’s “unconquerable disease” or refusal of treatment; and “the calamities of surgery or those accidents and complications over which we have no control.”³ He proselytized throughout medicine, particularly in the surgical community, that people should be keeping track of what they did, learning from it, and sharing that information. In a fit of frustration in a printed report to the trustees of Massachusetts General Hospital, he said, “Our charitable hospitals do not consider it their duty to see that good results are obtained in the treatment of their patients.” Codman realized that “it is against

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the individual interests of the medical and surgical staffs of hospitals to follow up, compare, analyze and standardize their results” for three reasons:

- ◆ Physicians and surgeons fear that perhaps their results as a whole will not favorably impress the public.⁴
- ◆ Data collection and analysis is difficult, time consuming, and troublesome.
- ◆ Neither the hospitals nor the public are willing to pay for it.

Eighty-five years later, exactly the same reasons are provided for why we do not document the quality of health care in this country. As Codman cynically expressed it, “If it is only for the interest of the patients, the public and medical science, why worry about it?”

Codman was not concerned about the possibility of public disclosure of medical outcomes. He wrote,

To the layman who chances to read this paper, the fates of these cases may seem far better or far worse than his imagination had allowed. But we believe that few surgeons would say that these are not excellent results. Therefore, why should not the layman see them as well, if he cares to? Why should he not look further and study the reports of all the hospitals for himself, to learn where such and such a branch of surgery is well done?

Let’s fast forward to the present. Today, managed care executives, like Dr. Lawrence, as well as purchasers clamor for this information to help drive a successful health market.

Evidence of Patient Demands for Information

Anecdotes from Focus Groups

The Foundation for Accountability (FACCT) has conducted focus groups around the country to learn how people respond to the questions: What does the American public think about the quality of care they are getting, and what do they want to know? Here are some of the things they have told us. The nature of qualitative research being what it is, these are obviously not completely random samples.

Lisa, a mom in Chicago

I mean I didn't know. I just went through when I picked my doctor, I went eeny-meeny-miney-mo, you know? I didn't know what to do. I didn't even know how my child was doing, like what his milestones were supposed to be. Like he's supposed to be sitting up at this age. Thank God my neighbor had children, and he's like, 'Lisa, he's not holding his head up,' you know? So I went to the pediatrician and he would tell me 'Oh, Lisa, he's just being a little pokey, you know, just a little pokey.'

So Lisa, a mom with Medicaid insurance, had to become her son's advocate and do battle with the American health care system. She had to be brave enough to tackle the system and the various barriers to care and access that she encountered. She continued,

Every time I called the pediatrician, he didn't even want to talk to me. It was like, 'Oh God, here's Lisa again,' you know?

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Eventually her son Kyle was diagnosed with cystic fibrosis, but it took her years to press through the system to get this diagnosis and the appropriate care.

Two women from Orlando, both diagnosed with breast cancer

One tells a positive story.

When they got my test results back, my doctor called me up that night and talked to me for about an hour, and that made me feel so good. My God, that's terrific, you know? It gave me a lot of confidence that, boy, he's going to take good care of me now.

Sitting next to her around a table in a conference room was a woman who said, *"I got a message on my answering machine with the results. And that was it."* You see the difference there.

An older person from Seattle

The doctor that I had when my diabetes was discovered didn't have much interest in me, so he put me in the hands of a nutritionist and then kind of set me loose. And his medical assistant, who's the only one who really had an interest in me, retired. For 14 months I kind of went on my own. I finally decided, well, I'd better take charge of this. So I changed doctors. Now I have a doctor who's doing what I think she should be doing.

A hospital patient's wife from Orlando

The doctors and the staff, the nurses and all, they think we're there for their convenience. So periodically, when my husband was really ill, I would let them know in a nice firm way that I was paying the bill, I was paying Medicare, I was paying the HMO, and they're there for my convenience. A lot of the medical profession—the doctors, the nurses, hospital administrators, the whole ball of wax—they forget who's paying the bottom line.

These are just a few individual anecdotes, and you can dismiss them as the price we pay for a large, complex health system in a very diverse country. But we have spoken with hundreds of patients and family members from all walks of life, and we find a widespread sense of alienation and disenfranchisement, for many reasons, based on many personal experiences.

Aggregate Data from Patient Surveys

While there are individual anecdotes that are very troubling, we also have access to confirming data from opinion surveys. In 1996 the Picker Institute analyzed focus groups and surveys conducted by the American Hospital Association, along with its own survey data, to “explore public perceptions of health care and hospitals.”⁵ Of more than 20,000 hospital patients surveyed, between 22 and 28 percent reported problems in the areas of “respect for patient preferences; coordination of care; access to information and education; emotional support; involvement with family and friends; continuity and transition.” In comparison, only 10 percent reported problems with physical comfort.

Surveys of 13,000 outpatients in medical clinics and doctors' offices obtained these responses to questions about obtaining

appointments, waiting in the provider's office, obtaining information and explanations from the provider, being involved in decision-making, and being treated with respect and courtesy.⁶

In 1996 the federal government did a survey, asking people what they wanted to know about the quality of their health care.⁷ Eighty-

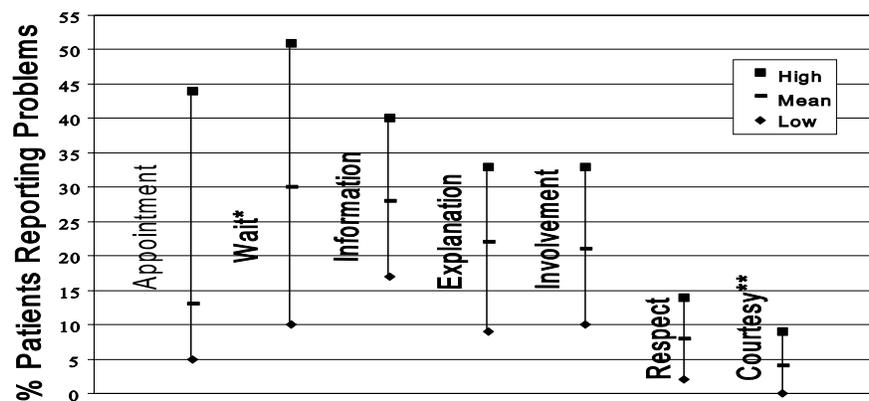


Figure 1 Problem rates for clinic and doctors' office patients.

Questions and response chart reprinted with permission from *Eye on Patients: A Report from the American Hospital Association and the Picker Institute, 1996*.

*Wait: percentage answering "yes." **Courtesy: percentage answering "fair" or "poor" on a 5-point scale.

seven percent of Americans in a random sample wanted to know about the quality of their health plans, 86 percent about the quality of their doctors, and 83 percent about the quality of hospitals.

These are not esoteric or marginal concerns. While keeping the costs of benefits low is still important, 91 percent of Americans want to choose a health plan with high quality of care. This is a vital and immediate concern across the board.

A Problem of Trust

When we ask people where they would go to get trustworthy information to help them navigate the complexities of this market, we are warned of a problem of trust.⁸ Nineteen percent of people trust their employers to tell them the truth about their health care, 12 percent trust medical plans, 9 percent trust the AMA and other medical societies, 29 percent trust individual doctors, and 50 percent turn to friends or family for advice about a decision that may vitally affect their health.

Focusing Health Care Reform on Consumers

We're not going to see national health care reform. We're not going to see the federal government write a law that changes how our health system works, that restores trust and rebuilds relationships. So how can we work our way out of this difficult time? Can we do it by piecemeal tweaking of financial arrangements, by changing PPOs into HMOs and point-of-service arrangements, by forming medical groups or disassembling Columbia HCA? What will lead to a comprehensive improvement in the ability of the health system to meet the public's needs and concerns? Two things have to happen.

First, we need to be sober minded about the realities in which we're operating.

◆ *Health care is both a social and a personal good. We have a shared interest in each other's health and in the creation of institutions and infrastructure that preserve our collective health.*

◆ *The government is both unwilling and unable to significantly shape the American health system. It cannot alter what happens between you and your health care professionals in a*

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meaningful way. Therefore, the strategies we use to shape our health system must be primarily extra-governmental.

◆ *There is a lot of public anxiety, but it is **not** about managed care.* Managed care is a response to a set of forces and pressures, and has its own issues and problems to be addressed. The anxiety and discomfort people feel is decades old. It goes far beyond managed care.

◆ *There are pervasive myths about health care and our role in seeking health care that make it difficult, but not impossible, for us to be the pro-active agents that we need to be.* Michael Millenson explored one such myth in his monograph on the history of accountability in medicine:⁹

Marcus Welby, M.D. [which premiered in 1969] was one of the most popular television shows ever. The genial family physician of the show's title, portrayed by *Father Knows Best* star Robert Young, was both caring and competent. He never worried about an insurer approving his referrals to a specialist, and no reviewer ever second-guessed his clinical judgment. As University of Pennsylvania communications professor Joseph Turow noted, Welby always 'made sure that his patients received cutting-edge care in the shortest possible time.'... Unfortunately, neither Marcus Welby nor the Golden Age of medical practice evoked by his name ever existed.

In 1967 Surgeon General William Stewart openly called U.S. medical care 'often of low quality, fragmented and impersonal.'... At a White House press conference [in 1969], President Richard Nixon spoke of a 'massive crisis' in American medicine and called for 'revolutionary change.'"

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And Millenson concludes:

False nostalgia notwithstanding, the old guild structure of professional self-policing demonstrably failed to protect patients from ineffective, inappropriate, and even dangerous care. Policymakers should not let the yearning for a mythical past obscure the need for a professional accountability that goes hand in hand with professional autonomy.¹⁰

Second, we need to forge a shared vision. If there's one single thing missing in our discussions of American health care, it's a common understanding of what we want it to look like: what we want our health care system to do and to be. There's a range of understandable opinions but no consensus or leadership. Today, health care providers and managed care plans want to mobilize their patients and their members to be partners in their care. They know that the most effective way to save money and to improve health is for people with diabetes or asthma to know how to take care of themselves, and for people who are risking a heart attack to stop smoking. Such a partnership has to be a core part of the trust relationship.

This vision implies a health care system that's driven by and responsive to the needs, preferences, and values of the public. The cornerstone of this vision is that every one of us is encouraged to take control of our health care destiny. And frankly I don't see any other way we can get from here to there except by becoming agents of our own health care. This is an enormous and critical task. How do we help millions of people make choices that create a more successful and effective health care system?

Essential Initiatives: The Four M's

Message. We need to help people understand the power and the importance of their actions. The health care decisions that we make shape this health care system. What we do matters. We understand the impact of our decisions when it comes to voting for a school bond measure, or in personal behavior and lifestyle decisions, but we don't think that way when it comes to our health care. In order to shape a more consumer-based health care system, we will need to undertake a campaign of public education, using a core set of clear, powerful messages that help people understand the power of their own actions.

Model. We need an understandable framework for thinking about quality. What questions are implied when we ask, "What am I looking for in my health care?" How do I organize my thinking? If I look at *Consumer Reports* to buy a car, I see reliability, brakes, air conditioning and service records. There's a set of categories for car buying that I understand. What are the categories for health care?

Measures. What information will help consumers make sound judgments about the quality of care they can expect from their doctors, hospitals, or health plans? Are there systematic ways of measuring and reporting the quality of care?

Movement. We need to act. Given an understanding of the situation, tools, information we can use, and a framework for thinking about quality, we have to actually make decisions and behave in a way that reflects our values, goals, and needs.

Let me talk about each of these in a little more detail.

Messages to Challenge the Myths

Here are four things we can say to people to help them to be more assertive in shaping the health care system.

◆ **Quality matters.** This is very simple, but we don't say it very often. We talk a lot about cost, a lot about benefits, a lot about coverage, a lot about access, but we don't talk about quality. We don't say, "It really matters that we get the best possible health care, and we're going to measure performance to ensure that we get the care we deserve. We're going to hold ourselves and our providers accountable for meeting those standards of high quality." It matters to our health, it matters to the health of the country, it matters to the economics of our country.

◆ **Quality varies.** Everywhere we look, we find enormous variations in the way medical care is provided and the outcomes people receive. The rates at which mastectomy vs. lumpectomy is used for early stage breast cancer vary 30-fold from county to county across the United States; the rates of caesarean section vary by more than double from hospital to hospital—for no known reasons relating to the health of the mother or baby. If people behave as if all doctors practice the same, or all hospitals provide the same care, there is no reason for them to think about their decisions, and any hopes for a health care marketplace are doomed. In reality, choosing a doctor or a hospital is literally a life or death decision—and consumers need to face that directly.

◆ **Quality can be better.** There are thousands of wonderful, well trained, expert physicians, nurses, technicians, and managers striving every day to be compassionate and effective in the care they provide. Yet we know from every piece of data available that quality can be better. We need to talk honestly about the serious deficiencies in our medical care system, to confront the unacceptable rates of medical error, the under use of vital

treatments, such as immunizations for children and beta blockers for people after heart attacks, and over use of dangerous treatments, such as hysterectomies and c-sections. Until we challenge the health system to improve its performance, we will remain victims of inferior quality care.

◆ **People's choices affect quality.** People can make decisions, and their decisions matter. It is possible for them to have information that helps them make choices which reward good quality care and take patients away from substandard caregivers.

A Model for Organizing Information about Quality

As people become prepared to evaluate their care and make conscious decisions based on personal objectives and societal objectives, they need a way to organize their thinking. This can be done through the five following categories:

◆ **The Basics.** Are you being treated like a human being when you seek health care? Can you get an appointment in a reasonable and prompt fashion? Are people civil, courteous, compassionate, and respectful? Do you understand what is said to you? If you speak Spanish, Laotian, Russian, or sign language, do you understand the meaning of what is said? If your cultural background is different from that of the providers who are speaking to you, do you understand what they are telling you in ways that really matter to your health? Are you part of the decisions being made? Are you an informed partner in your care? These are "the basics" because they are the basic expectations of any service-oriented transaction.

◆ **Staying Healthy.** Does your health care organization help you stay healthy? People should expect to be told that they need their flu shot or their mammogram. They should be coached on how to check their blood sugar. Children should be educated about

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taking good care of themselves: about not smoking, not doing drugs, about safe sex, and seatbelts.

◆ **Getting Better.** If I get sick will I get better? This is the most common expectation of our health care system. When we encounter an injury or an infection, or require simple surgery, we expect a full and complete recovery—a return to normal daily functioning. Does my health system succeed at returning people to normal life?

◆ **Living With Illness.** If I'm not going to get better because I have diabetes, hypertension, congestive heart failure, or another chronic illness, will my health care organization help me cope with it? Will they help me adapt to my illness and live as normal a life as I possibly can? Will they reduce the burden of my symptoms and the fear and anxiety of not knowing what to do?

◆ **Changing Needs.** When life-altering changes, such as death or disability, affect me or my family, will our health system help us cope? The health care system is responsible for helping us through these difficult transitions in the best possible way.

This is a simple framework, but it captures a lot of information. It gives us a simple way to organize what we need to ask ourselves, and to make sure that our health care system is providing us good care in these five areas.

Measuring Quality in Ways Consumers Care About

The third challenge is to determine the quality of care we're getting in these areas. We need to give people accurate information. We need to develop ways to measure good quality. For any condition you might be concerned about—breast cancer, heart disease, asthma or whatever it might be—there are three things you as the patient and the consumer need to know.

- ◆ **Steps to Good Care.** Is my health care provider following the best known practices for caring for that disease?
- ◆ **Experience of Care.** How do other patients seeing these providers rate their experience? Have they had good access to treatments and specialists? Did they feel adequately informed and involved in making decisions? Were they satisfied with their care?
- ◆ **Results of Care.** Are the treatments and services effective? Have they achieved the desired improvements in symptoms, in functioning? Have key disease processes been effectively managed? Have complications been avoided? Has life been prolonged?

These are all things that we can measure routinely. The use of a simple survey that can be filled in by patients in ten minutes will answer all of these questions. We don't need to pull charts, we don't need to abstract records and we don't need lab data. By simply gathering responses from patients, we can measure the level of quality being produced in an HMO, a specialty group or medical practice.

Movement

The logical next step is movement. People will have to make decisions that reward high quality care. Market pressure will shape our health care system. The choices people have today often aren't meaningful because they may be offered only one kind of insurance or care, or their choices are among equals because the panel and providers are all overlapping. People also lack the information they need to make good decisions. We have to have an environment in which people have real choices and a stake in those choices. The stake can be financial because it costs more to make these choices, or the stake can be vital; our health will be affected by the choices we make.

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How do we put this into action? How do we get 250 million Americans to begin to make decisions that will change the American health system? We've seen Americans change the way they think about such issues as smoking and the environment; how do we get them to change the way they think of the health care system?

We need to approach this change by bringing together the organizations that pay for health care—employers and governments—and the people who care most about the quality of health care—patients and consumers. Together we can craft a message to the American public and communicate it broadly. Together, we can coordinate the messages and information that the public receives and create the foundation for a new American health system that involves and respects every person.

What Happens Next?

More and more information exchanges are done electronically: on television, radio, the Internet or through kiosks in the workplace. We will find more and more entrepreneurs developing alternative ways of telling people how to manage their care. We're already seeing home monitoring systems that remind you when to take your pills and when to check your blood pressure.

Services will increasingly be provided outside of the doctor's office, in a less expensive and more convenient way.

Supermarkets have been experimenting with putting diabetes management programs in their pharmacies. While you are in their stores, you can stop by the pharmacy, where they will monitor your behavior and remind you about checking your blood sugar. So, routine chronic disease monitoring may be happening outside the traditional medical care setting. Nurse practitioners, pharmacists,

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and educators will all be deployed in different ways in caring for the population.

As the importance of chronic disease grows, as alternative ways of delivering care evolve, as consumerism and health care information increase, how should key health care institutions respond?

For one thing, we will need to change the way we pay for health services. The complexity of medicine continues to demand a payment system that creates responsibility for the health of people—and doesn't just pay individual fees for each visit or procedure or drug. But this strategy of tying payment to people and their results also means that we will need to reward providers who are successful with the sickest patients. The current financing system fails to reward excellence.

How will health care professionals continuously improve quality?

Doctors, nurses and others in the health care world have spent the last ten years vigorously developing ways of improving quality using scientific manufacturing and statistical process control methods. The frustration for many of us has been that this work has not been grounded in the public need. Health care professionals will have to direct their attention to improving the elements of quality that the public cares about.

What will the government's role be in this consumer focused health care system?

The government is a very large purchaser of health care, accounting for over one-third of all health care expenditures. If government agencies could exercise purchasing clout the way a company like General Motors does, they might accelerate the shift toward a

quality-driven, consumer-oriented health system. Unfortunately, governments face political, logistical, and legislative constraints that prevent them from holding health care suppliers to tough quality standards—and the public suffers as a result. In practice, the government’s most important role may be to establish the “floor” of quality performance and refuse to license or contract with organizations that cannot meet the minimum standards of quality. To assist consumers to discriminate among all of the organizations that exceed that floor, the government can establish common measures and reporting systems—much as the SEC and FASB have established common systems for helping investors to judge the performance of companies in the stock market.

Conclusion

Anthony Giddens, a renowned sociologist and the new director of the London School of Economics, describes the modern world as “post-traditional,” by which he means

that, though tradition endures in a society, it has lost the privileged status that once enabled it to trump all other contenders. Traditions must now justify themselves in the same manner as any other points of view. Everything is ‘constructed’ in a post-traditional society, and nothing is ‘given’; one must choose every fact of one’s life.... Even the decision to forego the dizzying collection of options afforded by the modern world, and conform to the status quo, is itself a decision. ‘Individuals have no choice but to make choices.’¹¹

It will be our job, first, to create a health care environment in which all Americans can make choices that reflect their needs, values, and preferences. And it will be our second challenge to help the millions of health care professionals who bring enormous skill, integrity, and

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compassion to their work to understand what the public expects of them. This is what we mean by accountability. Accountability is not a club waiting to fall on an evil doer; it is an exchange of understanding between those who seek and receive care and those who are passionate about providing it. So that together we engage every American in the improvement of our own health and the continuous improvement of the health system upon which we all depend.

Endnotes

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3. Codman, E.A., *A Study in Hospital Efficiency, As Demonstrated by the Case Report of the First Five Years of a Private Hospital.* Printed privately in Boston in 1917. Reprinted in 1996 by the Joint Commission on Accreditation of Healthcare Organizations, Oakbrook Terrace, Illinois.
4. *Ibid.*, p. 111. "Life is so full of deception, and human nature indulges in so many curious pretenses, that the practical man in any form of business or applied science cannot help feeling occasionally that it is useless to try to be absolutely accurate. He is commonly placed in the position where if he sticks to what he knows to be the accurate truth, he will lose the business which might help him making his living."
5. *Eye on Patients: A Report from the American Hospital Association and the Picker Institute, 1996*. Available from the American Hospital Publishing Inc. website at <http://www.amphi.com/eyeonpatients/default.html>.
6. The questions read as follows:
Q1: Were you able to get an **appointment** as soon as you wanted?
Q2: Did you feel you had to **wait** too long in the waiting

room?

- Q3: Did you get as much **information** about your condition and treatment as you wanted from your provider?
- Q4: Did the provider **explain** what to do if symptoms or problems continued, got worse, or came back?
- Q5: Were you **involved** in decisions about your care as much as you wanted?
- Q6: Did the provider treat you with **respect** and dignity?
- Q7: Overall, how would you rate the **courtesy** of your provider?

7. Agency for Health Care Policy and Research/Kaiser Family Foundation Survey, October 1996.

8. *Ibid.*

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