

Barriers To Serving The Vulnerable: Thoughts Of A Former Public Official

Policymakers' capacity to measure the impact of programs beyond their direct effect on the budget remains woefully inadequate.

by **Christine C. Ferguson**

ABSTRACT: In an environment of limited resources, the question of who is deserving and undeserving of assistance becomes critical. Policymakers' biases about whether a health condition is self-inflicted, as well as their perceptions about whether treatments are truly effective, play a major role—often unstated—in the allocation of resources. [*Health Affairs* 26, no. 5 (2007): 1358–1365; 10.1377/hlthaff.26.5.1358]

FOR VULNERABLE POPULATIONS, ensuring health care coverage and access to good-quality, appropriate public- and private-sector services is an ongoing, highly challenging proposition. Indeed, as a former public health commissioner and director of human services in two different states, and a fourteen-year veteran of the legislative branch at the federal level, I have found the debates over resources for our most vulnerable citizens the most difficult to navigate. I have observed a number of variables unique to vulnerable populations that often impede health officials' ability to put sensible, effective programs in place.

The term “vulnerable” is often used to include the poor, the medically underserved, the chronically ill, those with disabilities, those with mental illnesses, alcohol and substance abusers, and immigrants. For the purposes of this discussion, I use the broadest definition of *vulnerable populations*, to include any group of people whose health care needs exceed the average or who are “at greater risk [than the average person] for poor health status and health care access.”¹

During the decade I served as a state official, never was there a year without a budget shortfall, which was inevitably portrayed as a crisis of varying magnitude. Because health care spending represents such a large percentage of state budgets, the pressure was great both to find savings within Medicaid, public health, and public welfare programs and to defend against cuts in important investments in those programs.

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Regardless of how compelling the public health case or the cost-benefit analysis is for a program to serve the vulnerable, the arguments run the risk of falling flat with decisionmakers. Even after the initial approval of programs or services, there is an annual struggle in every public-sector budget cycle, or private-sector health insurance contract renewal, to fend off reduction or elimination.

I have often been asked to speak, both nationally and locally, about these experiences to grantmakers, advocacy organizations, and other stakeholders in this process, to help them frame the most effective arguments on behalf of those populations that seemed most often targeted for cuts in services. We are comfortable in those settings discussing the potential economic benefits and health outcomes of providing services to the vulnerable populations in question, but there is a layer to the debate that often remains obscured, even in the frankest of give-and-take conversations: policymakers' perceptions and biases about vulnerable populations and their disbelief in the likelihood of a successful outcome once a service or treatment is offered. I contend that it is this layer that must be uncovered and accounted for if we are to maintain services, test and implement new delivery systems, and expand coverage options for the most vulnerable among us.

Why is ongoing support for these services so uncertain? Why are documented long-term gains, unambiguous science, and well-reasoned public health arguments so easily ignored or downplayed when it comes to providing health care to the most vulnerable populations? The answers to these questions can be found by teasing out the relationship between the relative availability of resources, the extent to which a particular vulnerable group is thought to be "deserving" or "undeserving," and whether there is an agreed-upon definition of what *success* means in the treatment for a particular group.

Availability Of Resources

In allocating resources, state and federal decisionmakers are constantly required to make trade-offs between health care and other government investments, as well as choices within health programs as to which populations to serve, which services to provide, and how robust those services should be. The availability of resources is the driving force in decisions about care for the most vulnerable. It is the pressure that flushes out policymakers' biases and exposes the barriers that those advocating for vulnerable populations must overcome.

■ **Choices at the state level.** In my view, state-level budget battles highlight challenges faced by the underserved and vulnerable more starkly than do those at the federal level. The choices are simply tougher, because governors and state legislators in most states are constitutionally required to balance the budget every year. They cannot run from their constitutional duty; there is no political cover. As health care spending ranges from 20 to 25 percent of state budgets (that proportion includes both the federal and state shares for Medicaid and the State Children's Health Insurance Program, or SCHIP, but I contend that decisionmakers focus on the total

of both federal and state health care spending, a fact that predisposes them to sharpen their axes), and the growth rate greatly exceeds all other areas of spending, there is extreme pressure to find savings in health programs.²

■ **Competing priorities at the federal level.** The conversation about competing priorities takes place at the federal level with less intensity, because when Congress cannot come to an agreement, it is free to do nothing at all and raise the debt ceiling, or punt the question to the states by means of new mandates. Advocates for the vulnerable generally seek protection from the insecurity of the annual state budget process from the federal government through Medicaid, one of the primary providers of health services to vulnerable populations. Because Medicaid is a federal-state partnership and an entitlement, Congress can maintain or expand federally mandated coverage and service delivery rules and thus shelter particular populations somewhat from reductions in coverage or services at the state level.

■ **Struggles in the private sector.** Similar struggles over the allocation of resources take place in the private sector among payers—both employers and insurers—as the rate of increase in health spending continues. Should the increases be offset by boosting the contributions of employees, cutting back on the scope of services, penalizing people for being overweight or for using alcohol or tobacco, changing the range of choices, or some combination? These considerations are weighed against such things as wage hikes and reinvestment in the business.

■ **Identifying possible savings.** When budgets need to be balanced, or rates of increase kept in check, the pressure to identify possible savings mounts dramatically. The first step to alleviate the pressure is to look at such things as modifying delivery systems, reevaluating the comparative effectiveness of treatments, and managing care more effectively. Unfortunately, in an annual state budget cycle, these changes frequently cannot be implemented, and the results in either savings or better outcomes cannot be accrued within a year. In the meantime, the pressure continues to mount, and when that pressure is high enough, the underlying question of who deserves help and who does not often overwhelms the debate to the point that most public health arguments and scientific findings simply take a back seat.

The ‘Deserving’ Versus The ‘Undeserving’

The question of who is deserving of government subsidies and how much they should get is a fundamental issue underlying the allocation of resources. Whether we admit it or not, health services and coverage for vulnerable populations such as Temporary Assistance for Needy Families (TANF) recipients, prisoners, homeless people, and substance abusers are balanced against more popular priorities such as tax relief, economic development, education, highway improvements, and preschool and child care. These trade-offs are considered annually, and every budget cycle represents danger for these populations and services.

In the context of limited resources, whether the population and health condition in question is “deserving” or “undeserving” of support and care quickly be-

comes a key, although usually unspoken, point in the debate. Of paramount importance in that characterization is the perception of whether the condition is self-inflicted. In my experience, the way public and private decisionmakers view vulnerable populations can be divided into three categories: (1) those with health care problems that are the equivalent of an “act of God,” such as most forms of cancer, premature birth, mental retardation, and, to some extent, age (children and the elderly); (2) those with health care problems that are viewed as being their own fault, resulting from behavior that could be reversed if they only were to make better choices, such as the overweight or obese, substance abusers, prisoners, the homeless, single mothers, illegal aliens, the HIV-infected, and the poor; and (3) the offspring of parents who made “bad” choices, such as illegal immigrants, those on TANF, or substance abusers. My observation has been that the first group is considered “deserving”; the second, clearly “undeserving”; and the third, the children of the undeserving, occupying a middle ground.

■ **Examples of “undeserving” people.** An interesting example of that thinking was seen during the 2004 flu vaccine shortage. As did many other commissioners of public health, I made a series of decisions about the allocation of the private and public flu vaccine supply in Massachusetts based on the best knowledge available at the time about those at highest risk of illness or death if they were to contract the flu. Our position was that along with other high-risk groups, prisoners who met the criteria for high risk should be vaccinated—because prisoners who fell ill would require expensive, state-subsidized hospital care.

Other states made similar decisions, prompting a national outcry at the thought that convicted criminals might be vaccinated before members of the general public. A Michigan man who had been unable to find a flu shot for his wife, who had asthma, emphysema, and bronchitis, memorably said, “This deal with the prisons has got me so upset. ...I don’t think they should get flu shots over citizens who are at high risk. They’re being treated like first-class citizens, and we are second class citizens.”³ Neither the public health arguments nor the economic arguments regarding the likely taxpayer-funded hospital costs for infected, high-risk inmates could counter the sentiments of the public embodied by this man’s words.

Another example of this classification of “undeserving” is the treatment of the overweight and obese—a population I include in the definition of *vulnerable*. In times of budget cuts and rising insurance rates, the question of whether overweight people should pay more for the same insurance coverage as their normal-weight peers is often raised. At the same time, services to help people control or lose weight are routinely excluded from coverage in public and private health plans. An exclusion from one major insurer reads thus: “Any services or supplies provided for reduction of obesity or weight, including surgical procedures, even if the Participant has other health conditions which might be helped by a reduction of obesity or weight.”⁴ There is an overwhelming public belief that the overweight and obese are in that condition because they lack the willpower to change the be-

havior that leads to their condition. That conviction that the condition is self-inflicted is a bias that creates a high barrier to coverage for treatment, despite the general acknowledgement that we are in the midst of an obesity epidemic that is likely to have long-term health, economic, and social effects and despite the scientific evidence that a 5–10 percent weight loss can lead to major health improvement, which can translate into short- and long-term cost savings.

■ **Examples of “deserving” populations.** An example of a “deserving” population for which treatment has been successful in the past twenty-five years is people with developmental disabilities. Successful treatment is expected to result not in a “cure” but rather in an improvement, such as the ability to live in a group home or independently instead of within an institution, or even merely preventing the condition from getting worse. Furthermore, the individual benefit or the improved condition may actually be more costly for society rather than less. In addition, the numbers of adults and children with developmental disabilities are not lessening; they are increasing, at least partly because of improved diagnostic capability. Yet decisionmakers are able to see the value in expensive services for the disabled—in part, I would argue, because they see the condition as an “act of God.”

Even among the “deserving” vulnerable populations, there is a limit to the depth of services that policymakers and the public are willing to provide. For example, poor children often have health problems that are less common among middle-income children, and children with disabilities have health care needs that go far beyond those of nondisabled children. Mental health services stand out as a major need among poor and disabled children, and yet in many parts of the country there is a grave lack of pediatric mental health providers and services. The interaction between the health and education systems is critical. Yet, as evidenced by SCHIP and the debate in the Deficit Reduction Act of 2005 about Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), Medicaid coverage for children’s mental health services is viewed by many decisionmakers as a frill, because it is more extensive than the employer-based coverage that most middle-class children have through a parent. The idea of providing more-generous services to vulnerable children is troubling to many lawmakers, regardless of the numerous arguments in support of these investments, such as improving school readiness and increased savings in other public programs.

Even as debate appears to focus on what the evidence says from a public health or economic perspective, the undercurrent has nothing to do with science or public health but, rather, with whether a lack of discipline, willpower, or moral compass is all that is preventing a particular group from taking the steps necessary to regain their health.

Judging Successful Outcomes

In addition to the unspoken judgments about whether the vulnerable are deserving or not, an additional factor often comes into play: cynicism about whether

treatment will lead to a successful outcome. This “battle fatigue” among policy-makers, as I call it, falls into two categories: (1) the belief that on an individual basis, seldom will an intervention or service lead to a successful outcome or a “cure”; and (2) the belief that on a populationwide basis, the number of people who fall into a given vulnerable group is never reduced, but rather increases. Health care costs continue to increase, and the drumbeat for additional investments intensifies, but we rarely can declare success.

In the private sector, there is often a focus on the individual—will a particular treatment for a particular condition lead to the cure or elimination of the condition? But in the public sector, the focus is both individual and societal—will a program providing this treatment to a particular population reduce the number of people with this condition? In both, the dominant variable is often economic, and the question asked is whether a particular health service or program will deliver a “cure” for a “reasonable” cost.

When there is either a lack of clarity or outright disagreement about effectiveness and definitions of *success*, an inclination not to cover or provide treatment and thus spend limited resources reigns, especially when the population involved is perceived to be undeserving. Likewise, although certain treatments or interventions may be effective for some, if the larger societal benefit is minimal, there can be a sense that the investment is too generous and that people who have only mild versions of the condition are flocking to receive services.

Another factor at play is the prevailing perception that providing high-quality, comprehensive services will attract not only the desirable (taxpayers and job creators) but also the undesirable to a state or, in the case of the private sector, to a product. In insurance this is called adverse selection; in states it is called being a welfare magnet. A good number of decisionmakers and citizens in the New England states believe erroneously that their states are magnets, even when the available aggregated data contradict their anecdotal experiences.

Policy Recommendations

How can we use our understanding of the challenges in providing assistance to vulnerable populations to safeguard programs that are critical not only to their beneficiaries but to society as well?

■ **Test new treatment modalities and financing mechanisms.** First, because health costs continue to occupy such an enormous portion of state budgets, and because those costs are far outpacing inflation, it is essential that we continue to test, and experiment with, new treatment modalities, care management, delivery systems, and financial mechanisms. Resisting change and advocating for more of the same demonstrates a lack of appreciation of the very real problems faced by decisionmakers in both the private and public sectors at every level, as health costs rise at a rate that consistently exceeds overall inflation.

■ **Address policymakers’ biases.** Second, even in good times, and with good

management, experience has shown that the economic, scientific, and public health evidence does not alone make a compelling case for providing, maintaining, or improving services for any vulnerable population. We have to address head-on the barriers caused by policymakers' biases and perceptions. The extent to which they believe that a condition is self-inflicted absolutely affects their willingness to fund services. Too often, this issue is downplayed or ignored in the debate by both sides, yet it may be the deciding factor. I am not necessarily arguing that those biases and perceptions can be countered or changed, at least not in the near term, but rather that they must be recognized as a powerful part of the resource allocation equation.

■ **Manage expectations.** Third, in advocating for services for the vulnerable, we must be adept at managing expectations. That is, we must maintain a balance between the hope of complete cure for an individual or total elimination of a public health problem, versus realistic, incremental health gains for vulnerable individuals and groups. In my view, we need to change both the way we measure progress and how we judge success. Many outcomes that appear to be failures can be deemed wonderful successes when viewed through a different lens.

For the overweight or obese, for example, success may mean an incremental loss of 10–20 percent of excess weight, which may do little to improve appearance in a bikini but which has clearly been shown to lead to a significant health improvement. Even so, most providers, patients, and payers view a 10–20 percent loss as a failure because we are not using a definition that equates to improving health outcomes, but rather the all-or-nothing approach of losing all excess weight.

We must communicate to decisionmakers that individual improvement in health is not an all-or-nothing proposition. In this quest, it is critical that we have a clear and easily articulated definition of *success* in treatment—one that is realistic and that includes all related factors important to society, such as economic savings, improvement in public safety, or gains in school readiness. For the mentally ill, success may be compliance with a drug regimen, not necessarily a return to full mental health. For low-income children, success of a coverage program might mean improved health outcomes that contribute to an ability to perform in school, rather than the protection of family income in case of a catastrophic illness.

Having a clear and updated expectation for what is likely to happen within an entire specific vulnerable population is equally important as we attempt to manage expectations. For example, a strong health insurance coverage program for low-income families is likely to improve health outcomes for those families, but it is not going to reduce the number of families in poverty. Better screening and services for children with autism are not going to reduce the number of children with autism in the community and in the schools—indeed, they may lead to an increased number of children identified with special health care needs—but they will likely improve the ability of these children to participate in society in the long term. A different definition of *success* for obesity and giving more people access to treatment programs might not eliminate or even reduce obesity in the short term,

but such steps could maintain current levels of obesity, and that might be a major improvement over continued growth spiraling out of control. Sometimes just holding the line would be an excellent outcome, and we need to view it as such. In any debate, being clear and gaining agreement about what would amount to a success is a critical strategic goal.

■ **Measure programs' impact beyond their financial impact.** Finally, we must develop tools to measure results effectively and easily against the definition of *success*. In government, outcomes and cost-effectiveness are measured in departmental isolation. *Success* should be defined for vulnerable populations not only in terms of health outcomes, but also in terms of the impact on a wide range of societal imperatives, and it must be measured in that way. Yet we lack the capacity to look systematically at the impact of a health intervention or service in more than one area. For health programs to work their best and to gain the broadest political support, we must find a way to look not only at health outcomes, but also at the impact on such areas as productivity, quality of life, and educational attainment and to translate that impact as a cost or savings to federal and state programs. In Massachusetts, after sizable cuts had been made in substance abuse programs, the public safety community and the courts began to experience the impact, a consideration not adequately factored into the decisions in earlier debates because of an inability or lack of capacity to estimate the impact in terms of anything other than how many beds would be shut down and services eliminated. As the pressure on other areas built, we worked collaboratively with the entire public safety community to reestablish and better design substance abuse services.

Yet even after these kinds of experiences, of which we can all provide examples, our capacity to measure the impact of programs beyond their direct impact on the health care budget remains woefully inadequate. We must develop the tools to measure the broader impact of health policies. In showing the broader benefit to society, we can garner widespread support for programs that target the “undeserving” vulnerable. As a society, we have everything to gain from doing so.

NOTES

1. L. Shi and G. Stevens, “Vulnerability and Unmet Health Care Needs: The Influence of Multiple Risk Factors,” *Journal of General Internal Medicine* 20, no. 2 (2005): 148–154; quote on p. 148.
2. National Association of State Budget Officers, *The Fiscal Survey of States*, June 2006, p. 11, <http://www.nasbo.org/Publications/PDFs/FiscalSurveyJune06.pdf> (accessed 19 June 2007).
3. “Inmates to Receive Scarce Flu Shots,” *Michigan Daily*, 20 October 2004.
4. Blue Cross and Blue Shield of Texas, City of Lancaster, *Managed Health Care Prescription Drug Program*, Group no. 84758, *Certificate of Coverage*, 2004, p. 46, http://esbd.tbpc.state.tx.us/docs/M0575/70792_2.pdf (accessed 30 July 2007).