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Daniel Callahan

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THE OREGON INITIATIVE: ETHICS AND PRIORITY SETTING†

Daniel Callahan, Ph.D. ††

INTRODUCTION

THE PAST FEW YEARS have been remarkable for the array of proposals advanced to address the American health care crisis. Their very quantity and diversity, however, suggest the intimidating range of the issues before us. We have difficulty agreeing on the nature of the problem, in determining how to interpret the history and set of values that lie behind our simultaneously affluent and advanced, yet inefficient and inequitable health care system, and in deciding how to devise a political strategy that can bring needed reform. That is a daunting set of problems.

The great attraction of the Oregon initiative is that it proposes a bold and integrated way of dealing with these problems. It embodies at the same time a number of assumptions and strategies that are new in the national debate. It challenges the widespread belief that health care can and should be an unlimited benefit. It rejects the common presumption that no rational way can be found to distinguish and set priorities among the bewildering array of individual health needs and claims. It denies the tacit but widespread belief that an open, democratic process can not effectively be used to make painful policy choices, that they are best hidden from view. It calls into question the pervasive view that any plan which would deny to the poor health care available to the affluent is of necessity unjust and unacceptable.

These assumptions are unsettling. They go against the grain of a number of values and practices that have marked the American health care system. At the risk of over-simplification, let me try to specify what those values and practices have been. We have come, for instance, to believe that everyone has a right to decent health

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†† Director of the Hastings Center in Briarcliff Manor, New York.

care, and that such care must encompass the latest and the best high-technology medicine; "quality" care embodying the leading edge of medical progress has been the ideal. We have also come to believe, if we are political conservatives, that a freer rein to the forces of the market can give us the health care we need, or, if we are of a more liberal bent, that a government-centered program can do the job. We have had a powerful faith that, whatever the underlying political ideology, greater efficiency, better technology assessment, and more informed patients can lead to an affordable system. We have, above all, rejected what has now come to be known as the intolerable "R" word, that is *rationing* as a solution to our problems. We have, in brief, held fast to the belief, the hope, the dream, the vision, that if we are just smart enough, and tough enough, and optimistic enough, we can give everyone the advantage of unlimited medical progress at a reasonable price.

What have been the impediments to this wonderful dream? The most obvious and generic has been our old human nemesis, that other "R" word, *reality*. Reality takes a variety of forms: the high cost of continuing medical progress, particularly in an era dominated by chronic illness and the wasting diseases of the elderly; the social and technical difficulties of (and resistance to) technology assessment; unreasonable and overblown public and professional expectations for ever-improved health care; growing resistance to the higher taxes that might pay for better health care combined with a deep distrust of government as the vehicle for a more effective and equitable system; and, as a powerful historical legacy, a health care "system" that is as multi-fold, variegated, lush, and deeply rooted as a jungle garden allowed to grow at will. It is a "system" that is not a system at all, at least if that term implies a coherent, organized, and unified set of institutions, practices, and values.

The Medicaid program, established in 1965 to provide health care for the indigent, illustrates and exemplifies these problems. The kind and quality of health care provided under the program vary enormously from state to state; hence, in national terms, it is erratic and inequitable. The large and increasing share of the funds that go to long-term care for the elderly (about 40%), reduce by that amount health care for the poor of other age groups. The combination of curtailed eligibility in many states (some 40% of those below the poverty line are ineligible for Medicaid), and variability in the type of coverage from state to state, mean that there are no consistent national standards for a decent minimum standard of support. There is, for instance, no agreement at all on "medical

necessity," (the term employed in the original 1965 Medicaid legislation as the standard of adequacy). The internal politics of most state Medicaid programs means that the public is usually not aware of the way in which coverage decisions are made. They are often hidden behind a veil of bureaucratic mystery, saving both legislators and other officials from public scrutiny and accountability. For its part, the public—rarely enthused in any event about paying higher taxes—has had removed from its sight the actual impact on the indigent of its resistance to providing more funds.

The result is an effective method of shifting blame for the inadequate coverage of the poor: the public can blame it on the legislators, and legislators can blame it on a stingy public. All, of course, can make common cause against the waste and inefficiency of the system, which sees in every state the use of expensive but unassessed technologies, large amounts of money spent on management and bureaucratic costs, and a lack of any clear standards of quality or adequacy.

How does the Oregon initiative propose to cope with that situation? Others in this volume have described in detail the nature of the Oregon plan. I will extract the major principles that animate it and frame the moral issues that the plan raises. To meet the problem of access to health care, the plan provides coverage of all persons under 100% of the federal poverty level. To meet the problem of budget constraints within the context of that universal coverage, a priority system will be established; everyone covered by the program will be eligible for some forms of care but not necessarily for all. The priority system will be based on the analysis of a special commission. It will rank order the medical treatments that could be covered by the program; additional cost figures will be developed to show the financial impact of covering the ranked treatments. It will be the final responsibility of the legislature to establish an overall budget figure by working with the priorities and figures provided by the Commission. The legislature will determine how much money the state will commit to the program. The dollar amount thus settled upon will determine how far down the priority list of specific treatments the program will be able to cover, and it will be clear from that procedure which of them will not be covered.

The results of the entire process will be highly visible, and the accountability clear. Public unwillingness to pay higher taxes for better coverage, and legislative unwillingness to vote higher budgets, will directly be reflected in the level of coverage made available. Additional features of the program will provide incentives for effec-

tive and appropriate care, avoidance of incentives for over-treatment, a plan for improved employer health care insurance, and a method of funding designed to create an economically affordable system.

The ethical problems potentially raised by the Oregon plan fall into four categories that require scrutiny: (1) its moral context and political setting (including its ideological meaning); (2) its formal and explicit goals; (3) its means of achieving those goals, that is, its process of priority-setting, public participation, and public accountability; and (4) its practical implementation, including possibly unintended consequences.

THE MORAL AND POLITICAL CONTEXT

The context of the proposed Oregon plan is that of a present Medicaid budget which, in responding to a shortage of funds, has set its cutoff point for coverage at 58% of the federal poverty line; those covered by the Medicaid budget, however, receive a full range of services. The state has to date responded to its money shortage by manipulating eligibility standards rather than service coverage. This is a common tactic among the states faced with this situation. Under the new plan, by contrast, coverage will extend to everyone below the poverty line, but at the price of a trade-off, that of a limit to the range of services to be provided, a range determined by the priority-setting system.

What are we to make of this history? A number of points are morally salient. First, for those poor people whose income placed them above the 58% Medicaid eligibility level under the old plan, health care rationing was already a reality (some received what others could not have). The legislature had set the eligibility level by establishing a priority system based on income. Thus, it is hard to conclude that the new plan represents a radical departure from the old in its background assumptions: that not everyone can get all that they might need or want, and that some system of priorities must be set. What is different is the *way* of setting limits and the *way* of establishing priorities. The Oregon plan remains a system of setting limits, only now in a different way. The question to be asked is whether it is a more rational, equitable way.

The main criticism of the new plan is that the heaviest burden will fall upon AFDC mothers and children, the least powerful and most needy group. There will, however, be an exemption from the priority system of other needy groups, the blind, the disabled, and

the elderly (heavily but not entirely covered by other entitlement programs). The result will be to remove a significant number of mothers and children from their present privileged place in the Medicaid program and force them to compete with everyone else. This is a serious and telling deficit, but it is offset, in part, by the inclusion of additional previously excluded mothers and children who will now be covered because of an extension of the coverage up to 100% of the federal poverty line. Whether the overall benefit to mothers and children under the new plan add up to a better balance of health care for this group as a whole is not clear. If the balance can be determined with any clarity, however, it would be a relevant consideration in any final moral judgment about the Oregon plan. It is also possible, of course, that the Oregon plan could be amended to return AFDC mothers and children to a special place in the system.

Second, as a Medicaid program it is obvious that the Oregon plan is a plan designed for the poor, not those middle-class, affluent people covered more generously by private employer health plans. It could be said, in the harshest construal of its meaning, that the Oregon plan is a targeted rationing program for the poor that sets limits for their care in a way that will not be borne by their more affluent fellow citizens; the poor, that is, are discriminated against by this plan. The Oregon plan's context is a two-tier economic society now matched by a two-tier health care system.

The logic of this line of potential criticism is obvious: unless Medicaid recipients are provided a level of health care equal to that of the more affluent, it can be seen as unjust and discriminatory. At least it will be seen that way if it is assumed that the poor have a basic right to equal access to the level of care which the affluent can buy or have provided them by private employer insurance plans. The obvious question is whether, in fact, our society has accepted as normative a right to equal access for all persons. The answer would seem to be no, at least in practice, even if public opinion polls find rhetorical support for the idea.

The most serious issue for debate is whether, by changing the Medicaid program (even if the result might be a better program in many respects), the actual result is to reinforce an unfair system, one that should not exist in the first place. Does the Oregon initiative wrongly legitimate the absence of a universal health care system in the United States? Does it also wrongly legitimate the idea of systematically (through the priority system) depriving the poor of some forms of health care they could have if more affluent? How

these questions are answered will depend in part on two considerations. Is it wrong in all cases to improve health care programs for the poor by programs that are less than perfect, and is working within the boundaries of public support a wrongful compromise for legislators?

What seems clear in response to these questions is that the Oregon legislators have little room to maneuver. The gap between aspirations for a one-tier, ideal program and the political realities can be seen by the Oregon public's unwillingness to pay higher taxes to support more generous Medicaid programs. Thus it is the voters, not the legislature, that must bear the blame for the inability of the legislature to provide support for Medicaid recipients equal to what the affluent can afford to buy (or get from their employers). A hard but obvious truth emerges: unjust or not, discriminatory or not, the legislature must work with the resources available to it.

It's moral task, in that context, is to deploy resources in the most equitable manner. Of course a legislature that too passively accepted that situation, and did not provide the kind of moral leadership necessary to fight for a change, could be faulted. Perhaps they could do better. Even so, blame for the Oregon situation should not fall entirely upon the legislators. It should be appropriately apportioned to a tax-paying public that is unwilling to support a more generous Medicaid program.

At the same time, there is an important question that should not be begged: does the fact that the affluent can obtain forms of health care not available to the poor under Medicaid mean that the poor have lost an *intrinsic* benefit, or only a *comparative* benefit? Does the fact that affluent Americans have been able to gain access to almost any medical procedure, device or drug in the name of health, mean that a government that does not provide likewise to the poor under its entitlement programs is *ipso facto* unjust? If the private sector has not learned how to set limits, to say no, must the public sector do likewise? The answer to these questions must take account of the fact that the private sector also is working to set limits and to set priorities in its insurance and coverage practices.

Are we to imagine that a government entitlement program could provide unlimited access to the highest quality health care regardless of cost? The possibilities for such care are infinite, and no other country—even those with universal health insurance plans—provides that level of care. The wealthy everywhere can buy better care than what is available to them under government programs, if only because of their ability to travel elsewhere to get what

is denied them domestically (wealthy Canadians, for example, can and do come to the United States to avoid queuing).

What ultimately matters is not whether the new Oregon plan legitimates a two-tier system, one level for the poor and another for the wealthy. It surely does that—just as surely as does the present Oregon system, with its total exclusion of many thousands of poor people from the program. The new two-tier system plan is presented, however, as more equitable than the old one. The crucial question in that respect is not only whether the poor are worse off than the affluent, but also whether the care that would be provided under the new plan will be decent, humane, and reasonably adequate for most if not all legitimate medical needs of the poor. If that standard can be achieved (assuming we can define it with any precision), it could be judged reasonable and fair, even if the affluent and wealthy do better.

THE GOALS OF THE OREGON INITIATIVE

The goal of the Oregon initiative is to provide a basic and adequate level of health care for all of the poor (the 100% level), but within the externally-imposed constraints of a limited budget. These constraints in turn dictate that not all needed or desired care can be provided. There will be a ceiling on expenditures. The existence of a ceiling is, of course, a necessity in the case of a limited budget. The old ceiling was managed by limiting the eligibility to participate in the program (the earlier 58% poverty level requirement). The innovation in the new program is to manage the ceiling problem by making all the poor eligible, but then setting priorities to manage the available funds.

Is this a reasonable and fair goal? On the question of whether it is sensible and equitable to extend eligibility at the price of reducing coverage, no definite answer can be given. It is a classic question of prudence, not fixed moral rules. The consequences of these two approaches can and should be evaluated: full eligibility and less coverage versus less eligibility and full coverage. If one showed itself more obviously burdened with nonsensical or unjust outcomes than the other, a choice could be made between them. That is not likely in this case. Various incommensurable goods will have to be compared and no striking imbalances are likely to appear. Even if they do appear, however, none will be so dramatic that they automatically condemn the plan of which they are the outcome.

There is, however, one possibility that could make a real differ-

ence. If the coverage provided under the new plan systematically and continually deprived recipients of some crucial benefit, or benefits, that would drastically affect their health and lives, we might then conclude that it was unfair. That could only be concluded if two conditions were met: the first is that the program was unnecessarily deprived of funds by a niggardly public, and the second, that a reasonable effort was not made to balance the available resources to minimize that kind of outcome. Unhappily, of course, it could well be that even an otherwise rational priority-setting process might end by excluding some forms of care that are of intrinsic value and necessity to some individuals. Life-saving but expensive organ transplants might be an obvious example. If they end up as a low priority item, they are not likely to make the budgetary cutoff point. To limit coverage of such procedures for the sake of other healthcare benefits of an important kind would not necessarily be unfair. The right to a decent minimum level of health care need not entail coverage of each and every form of medical technology, no matter how expensive and how limited the number of beneficiaries. It is hard to see how any society could for long make a promise of that kind without doing damage to other health and social needs.

We are left, however, with a terrible problem once we recognize that kind of limitation. Might it be said that a process which resulted in certain forms of care being denied would be a *prima facie* unjust process—because the right to those forms of care is so basic to human welfare that any system that jeopardizes them must be condemned? The way in which the denial of what Albert Jonsen has called “rescue technologies” (those necessary to save a patient’s life), almost always results in acute public and professional discomfort (despite what an otherwise reasonable cost-benefit analysis might say) illustrates both the moral and political issue here. The denial of some forms of care will be seen as both morally wrong and politically unacceptable. If that is so, that leaves us with a genuine dilemma: in addition to a fair political process, will we also need some independent moral criteria by which to judge the outcome of the process? If so, will that not undermine the credibility of the process, making it subject, so to speak, to a moral veto if the results are unacceptable?

I see no way out of this problem other than to define a basic package of health care benefits available to all regardless of their ability to pay. If the Oregon plan could be amended to guarantee such a package prior to the setting of priorities for additional care, that would be enormously helpful to avoid the dilemma. Presently,

it looks as if the priority system might deny some forms of care that seem imperative, and that the price of avoiding such an outcome would be an arbitrary setting aside of the priorities. Some forms of care might be required to be available to all regardless of the priority they might receive if they had to compete with other forms in the political process; that is, they would be allowed to trump the priority-setting process. Of course too much trumping would threaten the credibility of the process; some therapies would be declared winners before the struggle over priorities even began, an unattractive prospect for those whose health needs would not be among the lucky pre-game winners. The creation of a basic health care package not subject to priority setting seems a preferable alternative, but it would of necessity exclude some important but expensive forms of acute care medicine as the price of making that package financially tolerable.

THE PROCESS OF THE OREGON INITIATIVE

How might such a set of problems be decided? Ineluctably, a consideration of the goals of the Oregon initiative must be a consideration of the means to achieve them. Must the process of priority-setting assume that a well-designed procedure will itself be tantamount to a just procedure, i.e., that any outcome that results from a conscientious, scrupulous adherence to the procedure will be declared just, as if that is what just *means*? To come to grips with this question two problems must be confronted. The first has been alluded to above: whether there are some health needs so preeminent that they must trump their way to the top of any priority list; or so important that their omission from any health care package based on the priority-setting process would tend to discredit the process altogether. Both of those possibilities could suggest a compromise of the integrity of the priority-setting procedure. Yet there may be no choice but to accept the need for such compromise.

The second problem is whether the design of the plan to set priorities is reasonable, organized to produce as fair an outcome as possible. This is hard to say in the absence of any experience with such a procedure. The absence of any clear community historical tradition or present consensus on the setting of priorities, and the absence of any established method of determining the comparative importance to individual welfare of different procedures makes it problematic to evaluate the plan's design. A safe assumption is that community support would be strong for the high priority of life-saving treatment, and a lower priority for treatments that affect the

quality and comfort of a life. What the community, and the Commission, will think of life-saving treatments that help a few people at a very high cost per person, or of a quality-enhancing treatment that can help many at a low per capita cost is, for the moment, less clear.

A priority-setting process that neatly and deductively builds upon available ethical principles and community sentiment and extracts from them a theoretically elegant and obviously acceptable set of priorities is not feasible. Instead, a more likely model is one that constructs a fresh way of looking at health care, one that will need to invent its own method and set of standards. It will require a unique blend of principled equity, supportable preferences, and community sentiment. Only over a period of time, after the priorities have been put into practice, can this new approach pass the test of ethics. The final test can only be that of experience: the process must be found satisfactory in practice. It would, then, make most sense to look upon the process as a social experiment, the invention of a policy out of the less than whole cloth of existing preferences and values. Its tests will be its public acceptability and independent of the process, whether their outcome is fair. Since there are no commonly accepted norms available to provide a wholly independent standard, there must be continuing public discussion and debate about the balance between good process and good outcomes. That is hard work, but a necessary part of life in a free society that strives for procedural justice, yet, recognizes that moral claims may, on occasion, transcend what can be achieved by procedural means alone.

One of the purposes of the Oregon process seems to be to serve as a goal to the public. By informing the public that the money they are willing to pay in taxes will determine how deep the coverage of individuals will be, that is, how far down the priority list the funds will allow the state to go, the public will ultimately be accountable for the welfare of the Medicaid patients. No longer can the consequences of limited funds be hidden or obscured by administrative obfuscation; the winners and losers will be known. The citizens of Oregon are being asked to accept a priority-setting system as well as to accept the pressure it will (and should) put on them to be more generous in what they provide as taxpayers. Will both the public and the legislators be able to stand this kind of bright, cold light of accountability? That remains to be seen, but it is, in any event, a unique way of making everyone aware of just what it is they are doing. There will be no place to hide.

PROBLEMS OF IMPLEMENTATION

What is likely to happen to the Oregon plan when it is actually put into practice? One can only anticipate likely problems, but it is not difficult to predict what some may be. One of them is the likelihood that powerful interest groups will feel aggrieved that the illness or condition for which they speak is not covered by the Medicaid coverage priority list. They will then mount a campaign to make an exception to the list, or if that is unsuccessful, to claim that the method of setting priorities must, of necessity, be wrong or unfair because it ranked their condition too low. The attachments of riders to legislation, the meeting of "special" needs and the specifying of exceptions to ordinary policy are of course staples of the American political process; and, however distasteful, sometimes necessary to accept as the price of an overall successful strategy, the making of an exception in order to save the package as a whole. That may be necessary in this case, should such pressure arise (and why should we expect interest groups that lose out to remain silent?) Too great a capitulation to such forces will sink the plan, the very essence of which is to cut through competing claims in the name of a reasonable ranking of priorities. (One reason I am told for early resistance to a waiver for the Oregon Medicaid plan was that it would wipe out mandated coverage for many conditions, thus undoing the work of earlier reformers.)

A closely related possibility might also be, not to deny the need for priorities, but to say that severe cases of conditions otherwise ranked low would not be unreasonable exceptions, not in themselves subverting the idea of priorities. Again, some flexibility might be possible here, but not much without risking the plan as a whole. A chief difficulty indeed with a set of priorities for various illnesses and conditions is that it will not be responsive to individual patient variation: a severe case of a low-ranked illness might be as potent in its effect on an individual as a mild case of a more highly-ranked condition. It is difficult, however, to justify exceptions of any magnitude, or the making of (otherwise valid) distinctions of this kind.

The greatest source of anguish in the implementation of the plan will come in learning how to live with, and to rationalize, its failure to cover some people whose condition will pull at our sympathies. This anguish will be all the greater when the victims are visible and when the accountability for their condition can not be evaded. This is the greatest logical and emotional problem created by any set of

priorities devised to meet any conditions of limitation: how do we learn to accept the consequences of actions we know to be right and yet whose results create such pain? We will, for one thing, always wonder if we are doing the right thing; doubts will nag at us. We will always wonder, for another, if it might be possible to relieve the pain by some strategem we have not yet thought of.

The likely price, however, of letting that pain triumph over our reasonable efforts to be fair will be to move the injustice elsewhere, to stint on the need for education, or roads, or housing—where issues less momentous than life and health seem at stake. For just that reason, a resoluteness will be necessary to make the priority-setting plan work. There will always be what I have come to think of as a “ragged edge,” that line which separates what we can do, in fact, in contrast to what we might do in theory. An ability to tolerate, and live with, that ragged edge is imperative to make the Oregon plan work.

SOME FINAL THOUGHTS

I have tried here to raise what seems to me the most important moral problems that need to be thought about in judging the Oregon initiative. The most obvious general problem is: where should we start in thinking about health care in Oregon? Ideally, we should have a universal health care system in the United States and mandated federal and national standards for such a system. The present system is both unfair and administratively chaotic and expensive. Most of the maneuvering over the Oregon initiative should be seen as a response to those national shortcomings, and yet, both the old program and the proposed new ones partake of those shortcomings.

Should we then oppose the Oregon plan? Should it be rejected as just one more patchwork effort to redeem and legitimate an inherently defective system? I confess to deep ambivalence here. There are no signs at present of a universal health care system in the immediate offing in the United States, although there are growing pressures in that direction. Does it hurt the cause of universal health insurance to tolerate interim, less-than-perfect solutions? One side of me wants to say yes, and to offer the following slogan: eschew incrementalism. It might, that is, make it *harder*, not easier to gain a decent universal system if we continue to find ways to slightly improve the present fragmented system; we allow some steam to blow off, everyone feels a bit better, but nothing substantially changes. The 1965 Medicare and Medicaid programs were

meant to be the incrementalist precursors of a universal health insurance program of the United States. It did not happen. There is, then, reason to be wary of piecemeal approaches.

Yet another side of me wants to take better account of the present realities, not forever holding out for ideal solutions that may never appear. Among those likely realities are that we will not in the near future find a way to assess all, or even most, of our technologies, introduce dramatic cost-saving efficiencies into the system, or persuade the public to radically increase their tax burden. It could take years before we get anywhere close to those laudable goals. The popular idea that we should never put in place any rationing or priority scheme until all waste and inefficiency have been wrung from the system has two major flaws. One of them is that serious cost containment and waste reduction would themselves have to make use of many of the same techniques used in rationing and priority-setting: tough discipline, guidelines and protocols for treatment, denial of some forms of care believed efficacious by many practitioners, and so on. The other flaw is that it amounts to little more than a subtle way of maintaining the status quo, particularly since we know that the historical record over twenty years shows an almost unbroken period of failure to significantly reduce health care costs. Given that record, why should we believe that it can or will work in any substantial fashion in the near future? To cling to such a hope in the face of that history guarantees continued paralysis.

If we can accept the idea, then, that there is a kind of folly in waiting until everything is ready for some ideal system before taking some reform steps now, then the Oregon initiative promises a helpful step forward. Its goal is to introduce immediate reforms into a bad system. If, as its proponents hope, those reforms have an effect on all forms of health care in the state, private as well as public, they will have put in place some important ingredients of an eventually decent system.

At the heart of the Oregon effort is a simple perception. If a Medicaid or any other health care budget must be limited, then it makes sense to set priorities as a way of most effectively using the available funds. It is hard to fault the theory of this approach. Indeed, the chaotic nature of the present system, with its erratic coverage and mixture of mandated and non-mandated coverage, shows what happens when there is no priority system. I happen to believe, moreover, that we will never have universal health insurance until the Congress is persuaded that there can be a way of controlling the costs of such a plan, and a way of specifying some boundaries to

what it will cover. Congress will have to start with the premise that it can not provide coverage for all the health care that will be desired, or perhaps even needed. It will then have to know how to say “no”—effectively, rationally, humanely. A priority method, based on some combination of technology assessment and public preferences and values, is one of the only *conceivable* ways of bringing that about (and I can not actually think of what the others might be).

On balance, my own inclinations is to support the Oregon initiative. It has a number of practical problems associated with it, and the potential harm it might do to women and children is a serious (but probably correctable) flaw. Assuming a genuine effort to make corrections and adjustments, we have few more promising routes open to us in this country. Universal health insurance is an important and imperative national need. Its absence is a national scandal, and it can not come soon enough. In the meantime, however, we must work within the available limits of resources and public unwillingness to pay higher taxes. It is not enough, but it is the best we have. It deserves a chance.