A Debate on the Ethics of Aging: Does the Concept of Autonomy Provide a Sufficient Framework for Aging Policy? 1

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This article presents a debate on the issue of autonomy in aging policy held at the 1994 annual meeting of the American Society on Aging held in San Francisco, California. Harry R. Moody, Director of the Institute for Human Values in Aging at Hunter College, supports a reconceptualized notion of personal autonomy which focuses on issues of power, theory, and practice and finds conflicts between autonomy and justice in the lived world of the elderly and disabled. In aging policy, he promotes an emphasis on social movements such as Hospice rather than on autonomy of individuals. He suggests alternatives to extreme paternalism or complete autonomy, such as a communicative ethics approach. Larry Polivka, director of the Florida Policy Exchange Center on Aging at the University of South Florida, affirms that policy for the aging and disabled should be based on a commitment to autonomy. He describes an integrated model for long-term care that places autonomy first and includes features of the communicative ethics and negotiated consent model, and the virtues model.

KEY WORDS:

Father Fahey: We will have two presentations. One generally affirming the notion that autonomy is a central, if not the central, principle in our work. A second presentation that will say that is inadequate. There will then be a brief rebuttal.

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Larry Polivka: This is really a privilege for me to have a chance to engage with Dr. Moody on this issue. For the last 20 plus years I have been involved in very practical issues related to politics and policy in health, aging and other public-policy areas. For the last four years I have been working in the aging area, first as director of the aging program in Florida, and for the past three years at the University of South Florida as director of the Florida Policy Exchange Center. It has become increasingly clear to me that we can't live by economics and cost-effectiveness analysis alone when it comes to creating programs for older people, when it comes to thinking about what kind of policy we want in long-term care.

How do we determine what is right in the area of policy for the elderly? This issue has been a major concern for me since the 1970s when I worked in the area of developmental services. I was impressed by the moral commitment on the part of professionals and advocates for the retarded when it came to developing programs and policies. Some of you may be familiar with some of the concepts from that era such as, normalization of life for retarded people based on a rigorous commitment to autonomy, or on efforts to achieve the conditions that would make it possible for retarded people to be autonomous and exercise as much freedom as they possibly could. One of the things that became apparent to me in the last few years since I've been dealing more specifically with aging issues is that we lack a model that is dedicated or committed to the autonomy principle in aging policy that I experienced when I was working with the developmentally disabled community. The reigning paradigm in the developmental disabilities community today is a deep commitment to autonomy.

I think what Harry Moody is trying to do is make the point that we may have an excessive emphasis on autonomy when it comes to medical ethics generally and specifically in long-term care that has led to client neglect. We really need to move toward is a greater emphasis on what Moody calls negotiated consent—less emphasis on informed consent, which is one of the major concepts under the autonomy principle, and move toward a concept of negotiated consent that he draws from the work on communicative ethics by social theorist Jurgen Habermas.

Moody also offers as an alternative to the autonomy principle, a model of virtue ethics that places emphasis on virtues of courage, compassion and wisdom. He concludes that autonomy should not be elevated over communal relationships, that emphasis be placed on negotiated consent due to the realities of dependency, particularly in institutional settings, including nursing homes, and that greater emphasis be given to the development of methods for achieving consensus among the affected parties which would include the patient, families, professionals working with the family and patient, and others. I think that places policymakers in the position of risking the slippery-slope problem.

From my viewpoint, our biggest problem is not so much an excessive emphasis on autonomy but not enough. We haven't taken the need to preserve,
maintain and protect the autonomy of older people seriously enough to really develop policies and programs that reflect a commitment to autonomy. I think that’s most evident if you simply look at the landscape of long-term care. Ninety percent of the public dollars for long-term care go for nursing home care, even though we have been trying to develop in one form or another community alternatives for the last 20 years. Many states for the last five years have seen a decline in funding for community alternatives because of fiscal crises. States have been reducing general revenue programs and protecting the entitlement programs under the federal government, including Medicaid-funded nursing homes. The programs that have represented the most advanced effort to achieve the autonomy of clients have been the ones in greatest peril, and the programs that place the least emphasis on autonomy, that is institutional programs, have been the ones that have been increasing most rapidly. Institutional programs under the Medicaid program have increased steadily in funding since 1988; and the community programs, if you factor in inflation and population growth, have declined. Those are not the trends if excessive emphasis had been on autonomous programs.

I conclude with a compelling vision for long-term care reform from an ethical perspective that places the emphasis on the autonomy principle. It would include features of all three models that Moody discusses, the autonomy and rights model, the communicative ethics and negotiated consent model, and the virtues model. It would be an integrated model that gives first place, however, to autonomy that would emphasize individual rights within a communal context and recognize the need to negotiate the autonomy of disabled individuals. In practice, an integrated model based on the primacy of autonomy would require qualitative changes in the current system of long-term care. Most importantly, it would require the creation of a full array of long-term care options from in-home to assisted living and other alternatives to nursing homes that would provide enough choices for individuals to have something to negotiate about.

Presently, that is not the case. We should construct a long-term care system designed to accommodate a wide range of dependency and to maximize autonomy at every point, a flexible system of care that is responsive to individual needs and does not impose uniform practices within inflexible, institutional structures. We have barely begun to tap the potential of programs designed to expand the outer limits of dependency by providing resources for the exercise of autonomy. We have learned enough from our limited initiatives, however, to know how such resources can be effectively employed. Adequately funded in-home and congregate care alternatives to institutional care can provide opportunities for autonomy far beyond those currently available across this country.

If long-term care is to remain or become part of the life world of a civil society that remains largely unadministered, then it must be shaped by rigorous efforts to protect the autonomy of those receiving care. We must be prepared to improvise policies and practices in the interest of expanding opportunities for
autonomy. Negotiated consent should be understood as a vehicle for improvisation in pursuit of autonomy and authenticity. Nursing home care now absorbs over ninety percent of all public funding for long-term care and is a necessary part of any long-term care continuum. Nursing homes do not offer, however, the most favorable environment for undistorted communication, which is an important part of Moody’s concept of negotiated consent. An integrated moral vision that assigns first place to the autonomy principle could play a critical role in creating a long-term care system better designed to meet the needs and insure the rights of the elderly.

Harry Moody: Autonomy sounds great in theory, but practice is something else again. Autonomy betrays the life-world, the phenomenological experience of people—of the very people it’s supposed to address. There are fundamental conflicts between autonomy and justice, conflicts which are historically situated, and, in a sense, I think the age of autonomy is over. We need to take account of inequality, particularly of race and class, which makes autonomy very problematic. Autonomy needs to be reconceptualized radically as a developmental ideal, not simply the right to say no.

All of these, in one way or another, revolve around my conviction that we have to reconstruct the autonomy debate in terms of the issues of power, theory and practice. These problems are difficult. Mildred Solomon published an article in the Journal of Public Health based on research and interviews with practitioners. The article revealed that huge majorities of practitioners—doctors, nurses, and social workers in hospitals—don’t agree with the idea that we can collapse ethical distinctions such as, for instance, between withdrawing and withholding treatment. Practitioners think those options are radically different, although ethicists say no, they are really morally the same. Furthermore, many practitioners don’t accept the absolute language of autonomy. They acknowledge having routinely violated patients’ preferences and consent all the time in all sorts of ways.

Now you might hear this and say, okay, it’s not so good. We have to redouble our efforts, having lost sight of the goal. That is, we need to redouble our efforts because the practitioners still don’t get it. The trouble with this reply is that families don’t think that way either: they just don’t get it either. If you don’t believe me, look at the video tapes of a conference called “The Birth of Bioethics” and also at the video tapes from a conference held in Minnesota last year that brought together all the families, such as the Cruzan and Quinlan families, to talk for a couple of days about their lived experiences. When you listen to those families talk, they don’t talk the language of autonomy. They talk the language of religion and family over and over again. That’s their life experience. They want to be left alone to work it out. Now, I do not want to be misunderstood as a defender of nursing home status quo or of medical paternalism or professional imperialism. But those families were saying something
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very important which we need to hear, at the same time that we recognize that there have been real gains in terms of our case law and ethics.

The point is that the language of autonomy does not capture their lived experiences at all. It captures, in my view, the discourse of an elite group, just as in the case of international economic development. The people in the third world are speaking a different language than the elites of economic planners and development will never take place unless those languages agree, unless theory and practice match each other. The lived experiences are very different.

We need to acknowledge the conflict of ideals. Autonomy and justice clash. Justice reminds us that you can’t just demand anything you want. There are many interested and concerned parties, including nursing home aides, an often-overlooked group.

My observation is that we are in a whole new historical period now, and this was brought to my attention in the peer group meeting on ethics committees where there was a very interesting discussion concerning the question, Can we have ethics committees in an era of managed care and what is the role of ethics committees in managed care? Nobody had any language to speak about this because they realized that the whole revolution of ethics and patients’ rights over the last generation has been based on this autonomy model. Now we’ve shifted, just as we shifted historically, from a physician-centered ethics, which is where this history comes from. We shifted from medical paternalism, which was the 2,000-year-old tradition. Literally, the 1957 Salgo decision was the first time in the history of law that the term “informed consent” was ever used, and the term doesn’t even become popular until the 1960s. So the legal revolution is very recent in our society. Informed consent and autonomy doesn’t have a long history at all. The ethical ideal of autonomy goes back to John Locke, Kant, and John Stuart Mill. This is important because Locke’s whole concept of rights is based on distrust of the government, on distrust of people in power. That’s how this country got started. You don’t trust the king, the doctor, or people who have the power. The politics of distrust is widespread today. It’s one of the reasons why we have difficulty getting a health-care bill passed. On a clinical level the problem with our ethics is the same problem that Kant had. We want to talk about philosophy but we don’t want to talk about psychology.

Psychology becomes very important when we consider proxy consent to health care decisions as a means of respecting autonomy. The problem is that when implementing this autonomy model, the proxy feels guilty. Guilt isn’t supposed to be there, but it is. For example, I once talked to a doctor who goes around the country promoting advanced directives. I asked him: “Do you have one?” He said: “No, I couldn’t do that; I couldn’t put that guilt trip on my wife.” This happens more often than one realizes. The guilt is there, the psychology is there, but we ignore it, we don’t talk about. If we neglect psychology, as
Kant did, then we neglect the psychology of caregiving, the psychology of relationships, and we will blow it. My point is that, historically, in terms of where we are now, we have entered an era of scarcity, of allocation of resources. The rise of the autonomy model belonged to an era when we saw this shift from a physician-centered ethic to a patient-centered ethic. Now we’ve moved again, from a patient-centered to a society-centered ethic.

Autonomy, informed consent, all these things sound good. But practice is something else. For instance, what happens if they write the Do-Not-Resuscitate (DNR) order on your chart and then the nurses don’t come? Did you know that the nurses won’t come? There have been studies showing that nurses come less frequently to people with DNR orders. So DNR becomes an invitation to patient abandonment. The nurses don’t come because they have built into them the heroic model of medicine. We can say the nurses ought to change, they shouldn’t have that heroic model, and they should come anyway. We can say that writing a DNR order shouldn’t mean the withdrawal of attention. But we begin to understand that there’s a reason why minorities are suspicious of advanced directives. There’s a reason why people from working class backgrounds are suspicious. They haven’t gotten good care to begin with. They’re worried that their autonomy is going to be a pretext for abandonment and, in my opinion, they are not wrong. Until we take race, class, and gender into account in bioethics, we will miss the boat. We will, in fact, create more inequality.

Autonomy as a developmental ideal is much more than “just say no.” The ethics of autonomy began with the right to die, the right to refuse treatment. It’s easier to say no than it is to say yes, not just with regard to resources, but also with regard to the self. But there are dangers here. Are we going to tell old people who don’t want to be a burden, now you’re at the end of your life, do you want to refuse treatment? Are we going to give them autonomy now at this point when they’ve never had it before? Why are we so willing to promote autonomy around life and death decisions but we’re never willing to give autonomy to people in all the rest of life? That’s a question we need to ask because the crux of what I have been saying is that we’re not stuck in the model of either paternalism or autonomy. There are other alternatives and we need to think about those alternatives.

The communitarian critique is one that needs to be taken seriously in terms of the limits of virtue ethics. Instead, I tend to approach the challenge of autonomy in terms of communicative ethics. What is needed here is not an emphasis on autonomy of individuals but an emphasis on social movements such as the Hospice movement that actually changed the practice of health care. Change happened because we were not approaching it as individuals seeking rights, but rather transforming the nature of practice. We’re stuck in the language of rights. People who have been brainwashed into the autonomy model think that once you give up the language of rights, there will be nothing left to protect
patients. That’s the problem and we need a new cognitive map, a new way of mapping the moral discourse. Margaret Urban Walker calls it “keeping moral spaces open,” and that means creating spaces for communication.

In our secular society, bioethics with its idealized version of autonomy actually represents an elite, secular, humanist ideology promoted by a small group, but not necessarily shared by masses of people and not reflecting their lived experience. We need to remember that there’s a profound religious dimension to the discourse of ethics. When I was talking to my friend, Ron Mannheimer I said, “What am I going to say about autonomy?” He said, “Mention Kierkegaard. We don’t give birth to ourselves. We don’t own ourselves. Life is a gift.” In Kierkegaard’s view, the aim of ethics shouldn’t be self-possession but self-surrender.

Now, not everybody agrees with the religious perspective. This is a pluralist society; you don’t need to buy into religion. But buy into this at least—what people want, above all, is not necessarily autonomy, but dignity and respect. We need to find ways to give people dignity and respect even when they’re not in a position to exercise self-determination, for material reasons, psychological reasons, and all kinds of reasons. They still deserve dignity and respect. And I agree with Larry Polivka about the need to create political and social change that will ensure that happening, whatever the institutional location.

Larry Polivka: Moody thinks that the notion of autonomy exists in theory more than it does in practice. I very much disagree. I mentioned earlier my experience with people in the developmental disabilities community. That was very much a shaping experience, because those people talked first and last about the potential autonomy of the very disabled people. As a matter of fact, the two institutions in Florida that have been closed in the last 25 years were two retardation facilities in Tallahassee and Orlando that served the most disabled, tube-fed, retarded people. They put them in what they called a developmental cluster. They have done studies since then and discovered that people they had once thought not capable of anything are now doing many self-initiated things with training and support. The rationale for closing those two institutions, was that these people that were flat on their backs and tube-fed had the right to pursue as much self-development as possible, however limited from our perspective it might be.

That commitment to autonomy has also been the motivating force behind our efforts to develop what’s called the extended congregate care program in Florida, our assisted living program. Our whole effort to develop an assisted living program is to provide as much opportunity for autonomy as possible for the seriously impaired elderly. Our original notion was that this would be a program that would provide privacy, a home-like setting, and conditions of dignity and freedom of choice to people who had deficiencies in most activities of daily living. But behind all that practical negotiating and compromising was
a commitment to create programs that reflected as concretely as possible a commitment to autonomy of individuals. I frankly don’t see an effective alternative to that in a practical sense.

If you start talking about moving from a doctor-oriented to a patient-oriented to a society-centered focus in the area of care, medical care, long-term care or whatever, that concerns me. And it is one of my concerns about the future of health care reform and what it will mean particularly for older people under managed care/managed competition. We’re moving away from a patient-centered to society-centered health care policy. And we’re doing it without the debate that should occur.

In regard to spaces for creating communication, for consent and for communal considerations, I don’t think you’re going to have that kind of space unless there is some underlying deep commitment to individual autonomy. I don’t think you’re going to have effective regard for an individual’s dignity and respect, or the need for respect unless you develop safeguards designed to preserve that individual’s autonomy. People begin to make decisions for others if there isn’t some feeling that the person they are dealing with has a right to make a decision and we have an obligation to preserve that right and to extend it as much as we possibly can, whatever the circumstances and time constraints.

I think we’re going to begin to lose view of the individual. He/she will simply slip out of sight and what I referred to earlier as the slippery slope toward paternalism and professional domination will occur.

**Harry Moody:** Much of what you say goes back to a basic analogy between aging and other groups such as, the physically disabled, the mentally retarded, and other groups where you feel that normalization has been an effective strategy. I think there is much to be said for the idea of the least restrictive alternative. But I’m not sure that this analogy is fully effective, and I think we need to think more deeply and ask ourselves what are the differences between the life plans and the life world of the younger disabled as opposed to older people, frail people. If we don’t take those differences into account, we may try to design the one-size-fits-all plan for home care and there are real differences and interests between the younger disabled and the frail elderly.

Now there are those who believe that the autonomy model, the consumer choice model and the voucher model are the way to go. I’m suspicious of that approach because I see that voucher/autonomy approach as having lots of perils.

Polivka gave the example of assisted living. I think we need to think about the trade-offs and the commonalities between autonomy and community. Good nursing homes need not be dehumanized, oppressive types of places. They may create conditions for community. We need to look at the best practices and the best models available.

Polivka uses the term slippery slope, but in his examples he acknowledged that there would already be trade-offs between autonomy and other goods,
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which actually concedes my point that there are differences and that autonomy does not trump all other values. The key question for me is, What counts as fair negotiation? That to me is the big problem. When is a negotiation really a fair negotiation?

The health care reform deliberations in Washington—here’s where we run into the issue of justice versus restricting individual preferences. We have to accept the idea that there are tragic choices in life. As Calabresi put it in a book on tragic choices, we cannot maximize all values. And autonomy does not trump all others. When we make choices as individuals and as a society, we have to accept those limits and acknowledge them as such.

Father Fuhey: Cohen did a study of two different models of home care, one that would basically be an agency model in which the agency would be the gatekeeper and also would sort of be the case manager. The other being a vendor type of model in which the disabled person was given resources and minimal supervision and was able to hire, and so on. Cohen said something that has remained with me and helped influence my own thinking: “You folks in many ways have been inadequate in your advocacy of autonomy because least-restrictive settings aren’t the answer.”

In fact, the motto of Citizens for the Retarded has not been autonomy, it is, “This is the Time to Flourish.” Societal goals should not be freedom, but how do we help people to flourish? Its particular influence upon me was felt when the Catholic Health Association did a study in long-term care. It talked about continual care, maximizing choices, appropriate kinds of support, freedom, etc., that are integral to its national health reform. The title of the work is, *A Time to Be Old, A Time to Flourish*. The central idea of the work is that autonomy is okay, but it must be something more and that something more can never come just alone from the individual, but it has to be involved with a caring community and society.

Larry Polivka: It has to be a flexible notion. What I’ve discovered in the work that I’ve done is that you can start with a definition and simply talk about trying to preserve and extend individual choice and the exercise of freedom. But where it really makes a difference is where you begin to develop legislation, a statute, You begin to develop a rule or set of regulations that will govern the implementation of the statute. You begin to develop staff training programs, case plans, all those things at every step in the implementation and operational process.

This flexible notion of autonomy has to be made real. There are many opportunities for the commitment to this principle to slip in that process of 100 steps or more. That’s the thing that impressed me about the developmental disability community. It’s as if they developed a professional and advocacy culture based on the preservation of client autonomy, and a kind of faith in the potential of developmentally disabled persons to experience growth, which to me represented the ultimate in respect for the disabled individual.
Considering the younger disabled versus the elderly, I think that we’re in danger of making ageist assumptions here, because what I have discovered is that a lot of older people want to have conditions that will protect their autonomy as much as possible. Frequently, that means giving them the means to maintain themselves with chronic and deteriorating conditions, but never assuming that once you reach this point then somehow your autonomy will be qualitatively restricted. What they want is to be provided the means to remain autonomous as long as possible. I think that’s a majority experience with older people. In that sense they are not qualitatively different from younger disabled populations, or they shouldn’t be considered qualitatively different from younger people in the development of public policy.

Harry Moody: I don’t think people go to nursing homes because they want to. And I don’t think it is a novel discovery that nursing homes are really a last resort kind of thing. I think the real question is for us to think through the notion of a life course and what that means. We need to think about how that might be the same or different for the younger disabled or for frail older folks and what is the role of community here. I do agree with the observation about the culture of disability and the creation of communities that are empowered, communities that, in turn, can challenge the professionals and say wait a minute, listen to us, hear our voices. After all, we stand here in this room as younger people, but we are speaking on behalf of the older ones. Now that’s ironic. We wouldn’t accept that kind of situation, say, with regard to the women’s movement—imagine, a women’s movement run and organized by men, or the NAACP run by white people. It would be bizarre. But we don’t think it’s bizarre about the field of aging. For the aged we haven’t got that kind of mobilization of the life world as we have had with the disabled; it doesn’t yet exist.

Instead, we have what Carroll Estes calls “the aging enterprise,” which magnifies the voice of professionals in the service system. I don’t say this to indict us; after all, I make my living in this aging enterprise. I say this simply to bring it to consciousness so we realize the paradoxical aspect of our situation, so we can remember that some voices are not heard.

Audience Participant: I’m still having a problem in terms of definitions. Respecting the dignity of the elderly sounds a lot to me like respecting their autonomy. But then I hear respecting autonomy in the sense of making it possible for them or us to be self-sufficient.

Larry Polivka: That has been my experience with this issue and this kind of debate. And it doesn’t just go on here; it goes on either implicitly or explicitly day-to-day in your work, in family situations and in your own life. Sometimes it’s very clear. At other times it becomes ambiguous. That’s just the nature of this thing called autonomy. That’s what I meant when I said, “If we’re going to take the principle of autonomy seriously in developing policy, then it’s something that has to be confronted at every step in the public policy process because at any point it can become vague and slip away.”
I think that self-sufficiency is an important part of the notion of autonomy. And I think as Moody was just saying, self-sufficiency, to a substantial extent, is a result that is based on, or is very much affected by, material conditions and the extent to which you can collect enough revenue to provide the kind of programs that will give people choice within service settings. I do think that it's also possible to combine, at least when you're talking in practical terms about public policy, issues of cost-effectiveness with an interest in autonomy embracing initiatives.

Nursing homes are very expensive. We've had the notion for some time, ever since the channeling experiment, that community programs were no less expensive. Recent research indicates that intensive in-home programs, and now the assisted living program, probably are less expensive than institutional care. They're not inexpensive, however. And there will have to be some control of and limit on the provision of these services.

Those are practical limitations. But I don't think that means that the notion of self-sufficiency and independence is not valuable, is not applicable, is not practical when it comes to developing public policy. You keep that idea in front of you as part of the idea of autonomy and you advance it as much as you can day-by-day, year-by-year.

**Harry Moody:** I agree with what you're saying, Larry, but I get the impression that you're saying that maybe we need a new channeling experiment because you've got some new data that are going to change how we see the facts. And I worry about that because we in the aging business have made an argument that not only is our community-based alternative better for dignity, choice, autonomy, whatever, but it's also less expensive. So, if community-based services turn out not to be less expensive, then what have we got to fall back on? What will our moral argument be then?

From a political point of view, you have a weakness when you're arguing a cause by means of a cost-benefit strategy, because that's the kind of utilitarian argument where the facts could always prove you wrong. That's why principle-based claims are better in a sense, but also sometimes more divisive. In making an argument, in political rhetoric, we need what Plato would call mythos to go along with the logos, imagination to go along with reason. You can sell the idea of "nursing homes without walls," dignity for residents, and all that because people can relate to that language imaginatively and respond to it. They say, yes, that's how I want to be treated when I'm old, or yes, that's the right thing to do, that's how we treat people with respect.

In our culture we prize autonomy because we believe that's the way that we show respect to people. That's how we take account of them as moral personalities, to use Kant's terms. But equating dignity and autonomy is a danger. It is exceedingly important for practitioners not to be brainwashed by this language of autonomy because there are many situations where we disrespect people or act in an undignified way to them that has nothing to do with choice or
autonomy. The disrespect has to do with the way that we talk to them, the way that we behave toward them in a hundred small ways. In other cultures where people don’t have a lot of choices, they may still have a kind of dignity flowing from their position, their status, their role in life and so forth. But in most situations we don’t have that kind of dignity or respect for older people in society. So we end up saying, “Well they don’t have any dignity. Let’s give them more choices.” Of course they may not be able to act on those choices, or maybe we can’t collect enough taxes to pay for the services they need to have real choice. To speak of taxes here underscores the real problem. After all, collecting taxes interferes with people’s autonomy in a big way. Many citizens reject government or higher taxes and they reject them using the language of individual autonomy. I worry about autonomy because people buy into it too quickly and feel that’s a good reason for rejecting the taxes for services that could achieve the goals that you want and that I want for a more decent society. The appeal of autonomy has to be balanced by solidarity, by acceptance of the fact that we’re all in this together.

**Audience Participant:** How applicable is the notion of autonomy in the development of policies and programs for those with Alzheimer’s?

**Larry Polivka:** That’s one of the variables that make this a complicated issue. In the development of our assisted living program, the extended congregate care program, we wanted to make it possible for people with Alzheimer’s and other kinds of dementia to be in assisted living programs that would be especially designed for them. And that might well require that they have space for people to wander in. They couldn’t be confined to a facility or to just a small exercise area. They would have to have access to a park area. It would be a part of the program, as expensive as that would be. We had a pilot program in mind at that point that was going to convert part of a mental hospital’s grounds into an Alzheimer’s facility that would have had several acres for them. In part, because we were convinced, based on observation and the judgment of people I respected, it really did make an enormous difference in the quality of life for people with Alzheimer’s to be able to walk freely.

But what happened was that in our debate with the people who were resisting an extensive version of assisted living, we had to compromise. Our compromise was that people who could not make simple decisions, who could not choose between chocolate cake and apple pie, or would know the difference, could not be in one of our extended congregate care facilities. I think that’s going to have to be changed as soon as possible, but it’s going to be difficult.

For a long time we’ve had a very restricted discussion about programs for persons with Alzheimer’s, a very narrow discussion in terms of alternative settings for people with Alzheimer’s—congregate settings with locked units. That was the extent of it. The alternative was to have them in homes with caregivers who were being destroyed by the care burden. That’s not an issue that
we have taken seriously yet as a society in terms of the public policy issue or implications of it. It should receive a lot more attention. Programs for those with Alzheimer's should be far more developed than they are at this point, given the magnitude of the need.

Father Fahey: Does a two-year-old have autonomy or is he capable of autonomy? Certainly there can be spontaneous actions or self-generated actions, but it's not really a human act without the ability to bear some of the responsibility for what it is that occurs by reason of you acting. I think that's the correlative element to freedom or to individuality. There has to be some degree of understanding about what you do and its impact upon others. But that's two different kinds of autonomy. The question then in public policy is, Is it a management question or is it a question of human freedom and dignity? And I think those distinctions have to be made.

There can be a tyranny in our culture of the celebration of independence. I recall Maggie Kuhn speaking to us as a group. She had to sit during her talk. She wanted to impeach President Bush and a variety of other things in her conversation proved that she was absolutely intact mentally. At any rate, she could not stand. She said, "I'm at that stage in my life where I cannot stand without a loving arm, and that's okay with me." And in some ways she said more by that, in terms of the acceptance of dependency. I think that we can celebrate autonomy too much. Celebrate our culture and create unreasonable expectancies as if even at this moment I am autonomous. I'm not absolutely autonomous in any way, shape or form. I wasn't, I'm not and I won't be in the future. But again, like all these things, it's a continuum.

Audience Participant: Intergeneration, autonomy and their relationship; people reach the point they can no longer do the things that they used to do, but they still want to maximize all of the values that they can, to pursue their interests and choices as much as possible.

Harry Moody: Negotiation is a much-misunderstood term. A lot of people think of it merely as power: you win, I lose. But real negotiation involves trying to understand the point of view of the other person. More deeply, there is also a kind of "internal" negotiation where I negotiate with myself and make trade-offs. That's what you were alluding to in terms of not maximizing all values. When we do negotiate with people, whether it's in a marriage or a business situation, negotiation at its best is an invitation to deeper communication. It is an opportunity for me to reflect on what I really care about and what I am willing to give up, and that communicative process can be emancipatory, hopefully. But it doesn't always happen that way, I admit.

Father Fahey: I can't help but reflect about something I heard at the Gerontological Society a year or so ago. Paul Faustus, distinguished university of Berlin psychologist, speaks this way of how to grow old gracefully. It's a question of selection, optimization and compensation, which in a sense is the same thing.
We do it all through life anyway. I choose to be a priest and, therefore, I don’t have certain choices. When we’re younger and perhaps have more resources, there are a wide variety of alternatives. I choose, and so when I choose one and don’t get something else, there’s still lots of richness there. I’ll use scripture. Jesus saying to Peter, “When you were young, you went wherever you felt like, but when you get older they’re going to put a belt around you and you’re going to be led where you would not have otherwise gone.” And in some ways that’s the way it is; but, even in that, there are opportunities for this kind of negotiation.

That’s what national health care is all about. We cannot absolutize any one value. What we have is a whole series of conflicting values in national health reform. A whole lot of stakeholders, all of who have legitimate moral claims, but we cannot satisfy all of them. What we’re going to do is to socialize many of those kinds of decisions, which is a movement already employed in health care generally, in all varieties of ways, in which we not merely as individuals negotiate with one another, but we share all kinds of risks and benefits, and some are in and some are out.

The more that we come together and share resources and risks, the more negotiation there’s going to be at a whole series of different levels, the more allocation there’s going to be, the more rationing there’s going to be, the more limitation there will be on autonomy. It is the inevitable price to pay in sharing risks broadly, particularly those who are most vulnerable at any age and who are not part of the production system.

REFERENCES

Debate on the Ethics of Aging


