

Autonomy and Dependency in an Ethic of Care for the Frail Elderly

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P r e f a c e

This is the sixth volume in the Florida Policy Exchange Center on Aging's Long-Term Care Policy Series. The previous five volumes addressed a wide range of policy issues, including the relative cost-effectiveness of alternative long-term care programs and the potential impact of assisted living, managed care financing and service delivery systems on long-term care policy over the next decade. These technical topics are critical to any analysis of long-term care policy. They should not, however, be addressed without reference to the ethical implications of the choices we must make about how we will care for the frail elderly and other groups in need of some form of long-term care. This volume represents the Center's initial contribution to emerging discussions about the ethics of long-term care. It includes a paper on the relationship between autonomy and dependency in the development and implementation of long-term care policy and transcripts of a debate I had the privilege of participating in with Harry R. Moody during the American Society on Aging's Annual Meeting in March 1994. Dr. Moody has done as much as anyone to demonstrate the importance of the ethical perspective in the development of aging policy and I hope others will benefit as much from his ideas as I have.

Since the debate with Dr. Moody, I have modified my views somewhat on the role of autonomy in long-term care policy and practice. I now think that autonomy must be understood in the context of dependency and the limitations imposed by frailty. I still think that the preservation of autonomy is an extremely important goal in the development of policy. But the emphasis on autonomy must be tempered by a recognition of the realities of dependency and the ethical implications of the caregiving relationship.

CHAPTER 1

Introduction

We have not paid sufficient attention to the ethical dimension of the debate over health care policy for the elderly, especially the frail elderly with chronic conditions and impairments requiring long-term care. We have been absorbed with cost-containment, efficiency and cost-effectiveness issues and have tended to pay little attention to the many ethical and moral assumptions inherently related to these issues which are most commonly treated as technical matters.

The social sciences and policy analysis have produced a lot of information useful in the formulation of public policies in many fields, including health care. I do not think, however, that this kind of information alone is enough to develop policies that are best for the populations affected and society as a whole. We must also be prepared to address ethical issues as explicitly as possible and in as open and undistorted a manner as we can manage. The findings from social science research should be used to help construct a consensus, or at least identify points of agreement about the empirical realities of any policy subject addressed. This use of the social sciences can help create a clearing in which we can begin to discuss the ethical dimension of the policy issue at hand. The authors I discuss in this essay have incorporated the results of social science research into their work on ethics in precisely this manner, work that should, in my judgment, be given equal weight with the quantitatively oriented policy sciences in the formulation of health and long-term care policies for the frail elderly.

CHAPTER 2

The Ethical Dimension of Long-Term Care

In *Ethics in an Aging Society*, Moody (1992) makes an important and impressive effort to use the strategies and findings of the social sciences to inform our thinking about the ethical dimensions of long-term care. In this respect he has adopted the perspective of a leading social theorist, Jurgen Habermas, who has long practiced the art of justifying ethical standards, at least partially and however satisfactorily, on the basis of knowledge generated by the social and behavioral sciences.

Moody makes good use of Habermas's updated enlightenment project and its major product, the concept of *communicative ethics*, in critiquing the autonomy principle and the individual rights model as they are conventionally used by ethicists interested in developing an ethic for medical care, including long-term care. Our notions of autonomy best fit an acute care model, where a competent patient provides informed consent for medical treatment. Given the power of physicians to select the information provided and the solutions presented for consent, the concept of autonomy is problematic even here. Dependency, aging and chronic conditions render our concepts of autonomy more problematic in long-term care. Many would agree with Moody that the autonomy principle alone does not provide a sufficient scaffolding for a comprehensive approach to an ethic of long-term care. Moody rightly argues that informed negotiations between caregivers and recipients of care and professional judgment are clearly essential to the development of rational and fair long-term care practices.

Moody is also right to point out that:

. . . what we find in advanced industrialized societies is a condition of *systematically distorted communications*, which serve to frustrate free and open deliberations. In mass media, in the educational system, in the workplace, in political communication, everywhere we find an evasion or falsification of discourse. Instead of open deliberation, we see domination by power or manipulation. . . . Instead of freedom, we have the *colonization of the life-world* in old age, where the last stage of life is emptied of any meaning beyond sheer biological survival. . . . This whole development is part of a social and historical process, not at all a matter of individual choice. Therefore it is not surprising that the traditional ethics of individual autonomy has been helpless to halt this erosion of freedom. The ethics of patient autonomy may insist on informed consent or encourage advanced

directives. But those very instruments are comprised by the institutional structures and the systematically distorted communications in which the elderly receive care.

This is a wonderfully accurate and eloquent description of how we treat many of our frail elderly. I do not think, however, that giving up on the ethic of patient autonomy will lead to less distorted communication or halt the erosion of freedom.

The autonomy principle, which is based on the fundamental liberal values of freedom and the integrity and dignity of the self (the bases of identity in Western cultures), provides the framework for the legal concepts of competency, consent, and confidentiality. After years of legislation and litigation, these concepts have emerged as hard-won tools for ensuring that an individual has the rights to be presumed competent (rigorous criteria must be met to prove incompetence) and to control what is done to and for her (consent and confidentiality). These rights, if effectively enforced, protect autonomy (freedom) and help preserve integrity. In the last 20 years, the autonomy principle has been expanded to include the right to appropriate care, the absence of which may threaten a person's competency and her ability to exercise consent.

Why is autonomy important? What is the rationale for the claim that autonomy has primacy among the values we use to shape long-term care policy and practice or any other policy involving vulnerable persons? What is autonomy for?

I would argue that autonomy is an essential condition for the sense of self(ness) in modern society. Charles Taylor (1991) has described the modern era in terms of the concept of authenticity. We derive our sense of self from an original way of being. The creative sense of self appeared only in the modern era with the decline of hierarchical society and a shared sense of a divine order that characterized the premodern era. The romantic movement of the 19th century, with its emphasis on individual consciousness and sensibility, generated the framework for what Taylor calls *The Ethics of Authenticity*: the notion that one is obligated to develop the unique qualities of his/her own self. In its most popular form, this ethic has evolved into the concept of individual self-fulfillment achieved through the modalities of instrumental reason, i.e., the most efficient means to *some unique source of self-fulfillment*.

In Taylor's view, this is a very diminished (flattened and narrowed) concept of authenticity. It fails to recognize what Taylor calls the *horizons of significance* that make freedom (autonomy, choice) meaningful, and a sense of the *valuable@possible*. An authentic sense of self and meaningful autonomy are dependent on a background of intelligibility provided by horizons of significance that emerge from the historical context and all of the interpersonal relations that constitute our immediate world. In short, an authentic sense of self is dependent on our horizons of significance, which shape choices and channel the exercise of autonomy. Horizons of significance provide part of the equation that generates authenticity. The other part is autonomy, which is grounded in horizons of significance.

Taylor claims that:

Even the sense that the significance of my life comes from its being chosen@the case where authenticity is actually grounded on self-determining freedom@depends on the understanding that *independent of my will* there is something noble, courageous, and hence significant in giving shape to my own life.

But more: this minimum of degree of givenness, which underpins the importance of choice, is not sufficient as a horizon. It may be important that my life be chosen, as John Stuart Mill asserts in *On Liberty*, but unless some options are more significant than others, the very idea of self-choice falls into triviality and hence incoherence.

Only if I exist in a world in which history, or the demands of nature, or the needs of my fellow human beings, or the duties of citizenship, or the call of God, or something else of this order *matters* crucially, can I define an identity for myself that is not trivial. Authenticity is not the enemy of demands that emanate from beyond the self, it supposes such demands.

Autonomy then is important because it is a necessary (but not sufficient) condition for the creation of a valued sense of self and others (mutual recognition). For this reason it should hold a prominent place among the principles that guide the development of long-term care policy and all other policies that affect the status of vulnerable persons. From this perspective, negotiated consent (communicative ethics) and the virtues model constitute procedural safeguards designed to protect the maximum feasible exercise of individual autonomy. The preservation or expansion of autonomy should constitute the substantive content of negotiation and the goal of virtuous conduct. A rigorous adherence to the autonomy principle is necessary to avoid the slippery slope toward professional paternalism, and the emergence of policies and practices that mainly serve the interests of others—i.e., convenience of family members or service providers.

Moody has made a very valuable contribution to the growing debate about the future of long-term care. He reminds us that this debate has an unavoidably ethical dimension. Long-term care policy must be guided by more than narrowly defined criteria of efficiency and cost-effectiveness and an excessively narrow focus on individual autonomy. Our capacity to improve the quality and availability of long-term care will depend on our ability to articulate values and to construct a compelling moral vision. If this is not accomplished, purely fiscal considerations and power politics will determine the future of long-term care.

In *Autonomy and Long-Term Care*, George J. Agich (1993) makes a sophisticated argument for autonomy as the core value governing long-term care policy and practice. His argument is based on a critique of the concept of autonomy that includes many of the same concerns raised by Moody. The concept of autonomy derived from liberal theory with its heavy emphasis on individual independence, nonintervention, and rational decision-making does not provide a practical framework for an ethic of long-term care. It is too abstract and removed from the complex realities of long-term care. Like Moody, Agich's view of autonomy is grounded in a situated perspective that focuses on interpersonal relations, institutions, culture, and other contextual factors that shape the development of the self. In rejecting liberal theory's absolutist emphasis on the rights of independence and nonintervention (negative autonomy), Agich does not embrace the alternative of communalism, which emphasizes tradition rather than innovation and the community rather than the individual. Unlike Moody, he adheres to the concept of autonomy as the principle guiding value in the development of long-term care policy and in the conduct of day-to-day long-term care services.

As the basis for an ethic of long-term care, however, Agich's treatment of autonomy is complex and subject to the influence of many real-world variables that are excluded from the more conventional treatment of autonomy in liberal theory. For Agich, autonomy is more than just the power of an individual to keep others from intervening in her life without fully informed and uncoerced consent. Autonomy is also the power of an individual to interact and communicate freely with others, to give and receive affection, and to initiate actions that are consistent with her sense of self. This positive version of autonomy is especially important in developing an ethic for long-term care. Few persons requiring long-term care services fit the liberal theory model of the fully competent, independent individual whose goal is achieving freedom from intervention by others.

For Agich, this negative interpretation of autonomy is of limited utility in formulating an ethic for the care of dependent persons. He does not, however, recommend replacing autonomy in the hierarchy of values guiding the provision of long-term care. Instead, he proposes to enrich the concept of autonomy by bringing in the real world of the day-to-day life of long-term care recipients and by demonstrating how a positive notion of autonomy can shape policies and service strategies that help preserve a disabled person's sense of self and extend the boundaries of his or her own volitional capacities. Positive autonomy means looking at the world of long-term care from the perspective of an impaired individual's need and efforts to define and make a world that is consistent with her own identity.

Agich is not only critical of the limitations of the liberal theory ethic. He is also critical of the principles derived from the medical model of acute care, which he describes as inappropriate for long-term care. The ethic of acute care emphasizes the role of informed consent by a competent, unimpaired patient confronting relatively precise decision-making events involving specific medical procedures and short-term treatment strategies. This approach to informed consent is not an effective means of preserving autonomy in long-term care, where the lives of patients are shaped less by discrete decision-making events than by daily routines and styles of caregiving. The effective application of informed consent in long-term care is dependent on continuous, undistorted communication between the impaired person and her care providers. Agich refers to this approach as a *process* model of informed consent, as contrasted with the *event* model of informed consent in acute care.

Agich's emphasis on communication and negotiation reflects his intention to identify ways of protecting and expanding opportunities for autonomy in the complex real world of long-term care. A person's evolving sense of self and the need to choose activities and projects consistent with her sense of self does not end with frailty and long-term care. Autonomy in long-term care is preserved by listening to and taking seriously the unique life stories of the impaired person and providing the kind of support that helps her maintain her identity despite impairment and illness. This positive interpretation of autonomy is based on the recognition of human interdependence and the limitations inherent in the liberal theory model of complete independence, especially in the context of long-term care.

For Agich, autonomy in long-term care is achievable to the extent that the impaired person is able to identify with the choices she makes. She must not be forced to make decisions or adapt

to conditions that negate her integrity and sense of self-worth. Long-term care therefore must include a broad range of options and alternatives in order to maximize the opportunities for choices and actions that are consistent with the impaired person's sense of self and the need to maintain openings for her continued development. Even the most limited long-term care environment (nursing homes) should be designed to maximize opportunities for autonomy. This means offering supportive substitutes for the activities that the impaired person values but may no longer be competent to perform without assistance.

In his effort to identify the concrete possibilities for autonomy in the everyday world of long-term care, Agich conducts a phenomenological analysis of nursing home care, organized around the themes of space, time communication and effectivity. This analysis provides a framework for a critical assessment of the gap between *what is* and *what ought to be* as defined by an ethic of long-term care based on Agich's concept of complex autonomy.

The extent to which one can move freely within and across space and time is a critical parameter of autonomy and one of the most important criteria in determining the quality of life in any long-term care setting. Drawing on literature from the ethnography of nursing home experiences, Agich claims that nursing home patients have little control over the organization and use of time in the nursing home. Time is organized to support the bureaucratic routines of the institution. The patient's autonomy and sense of self are sharply diminished when the patient loses control over the scheduling of events and activities, which may have very little meaning to the patient anyway, given their group-oriented nature.

The loss of control over the flow of activities and the strict limitation on the array of choices a patient may have in determining how he can spend his time are not the only time-based ways in which a patient's autonomy and sense of self may be damaged. Agich uses ethnographic findings to demonstrate that patients need to spend time with staff members talking about their lives and their perceptions of relationships between their past experiences and present circumstances. The need may frequently take the form of simply asking someone to witness, however indirectly, the patient's suffering. The bureaucratic structuring of nursing home routines and the compartmentalizing of staff tasks, however, provide few incentives or time for this kind of intimate interaction between staff and patients.

In the absence of personalized communication, there is not much in the nursing home environment to confirm the patient's sense of self. Undistorted, personalized communication is a necessary condition for the effective expression of compassion and affection by staff members for patients.

Agich points out that:

Good long term care requires an attunement to the elder so that one knows her so intimately that one immediately recognizes when she is incontinent or confused. This kind of recognition is not a matter of performing specific tasks or maintaining specialized technical skills, but involves cultivating intimate social relationships that can only be understood by reference to effectivity, which is all-too-often over-looked and undervalued

as the stress on service and tasks impersonalizes care to the point where bureaucratic efficiency replaces any vestige of social or ethical significance for these basic acts of care.

The following passage from the concluding chapter of *Autonomy and Long-Term Care* summarizes Agich's critique of the conventional concept of autonomy as expressed in liberal theory and conventional medical ethics. He concludes that efforts to apply liberal theory and acute care-oriented ethics to long-term care have left many disabled elderly (and younger adults) stranded in a moral vacuum without the resources to maintain a sense of their own humanity.

Throughout this study an expansive use of the liberal concept of autonomy and independence and noninterference was opposed on the grounds that it is really a limited political/legal concept that is woefully incomplete for the full purposes of ethical theory. Its most notable deficiency is its failure to accommodate a concrete understanding of persons and the nature of ethical responsibilities in the everyday world. In various guises the liberal view of autonomy influences thinking about long-term care. For example, social perceptions that autonomy means independence leads to the attitude of counterdependence in which elders feel obligated to avoid anything that appears to involve dependence; society for its part supports this behavior by institutional arrangements that assure that the full price of independence is paid. The lack of adequate long-term care insurance, including home care services and support in this country, often makes illness or disability for elders an all or nothing choice: either one accepts full dependence in a hospital or nursing home because medical problems are not attended to in a timely fashion, or one struggles with the functional disabilities associated with the illnesses of being old without adequate care until disaster arrives. (p. 127)

The *Erosion of Autonomy in Long-Term Care* by Charles Lidz, Lynn Fischer, and Robert Arnold (1992) is an observational study of the effects of organizational patterns and routine practices on the autonomy of frail elderly persons in a nursing home and a residential care program. The authors' definition of autonomy includes the liberal theory emphasis on intentionality, freedom from coercion, and insistence that some criterion of understanding and deliberation is necessary for a discrete autonomous act. They also adopt Agich's concept of consistency as an essential feature of their definition of autonomy.

Thus one critical aspect of understanding how the nursing home environment affects the autonomy of the elderly concerns how the elderly individual's persona is affected by the environment. Are the past activities, current identifications, and commitments and envisioned enterprises respected and encouraged or ignored and demeaned?

The authors use participant observation techniques and, to a lesser extent, interviews and quantitative methods to examine the daily lives of patients and residents in a nursing home and in a less structured residential care program. Their major research questions focused on the degree of autonomy, as defined above, experienced by residents in the two programs. The study has several methodological limitations, which lead the authors to suggest that their findings be treated as hypotheses requiring further research. This caveat notwithstanding, their findings are largely consistent with previous research on nursing home care and the much more limited research that has been conducted on residential care, or what is increasingly called assisted living.

Among their more interesting findings are the following:

- C The families of patients and residents and the upper-level staff of the facilities strongly support autonomy. In practice, however, nursing home routines and line staff attitudes encourage passivity, and efforts by patients to act autonomously are treated as unreasonable demands. Families also encourage passive behavior, and both groups place greater value on physical safety than autonomy.
- C The ethos of the residential care unit was quite different. The caregivers here viewed promoting autonomy as central to their role. Autonomous behavior, rather than constituting a problem, was one of the primary goals of residential living. In the residence sustaining autonomous functioning, not health care, seemed the dominant value among line staff.
- C The amount of structuring and rigid scheduling of routine activities was strongly related to the cognitive and physical abilities of patients and residents. Even here, however, there was a substantial difference between the nursing home and residential units. Residents of the latter, cognitively capable or not, were allowed to spend much of their time as they like.
- C Residents of the residential care unit had greater privacy than patients in the nursing home, where almost anyone could gain unrestricted access to the patients' space.

From their findings, Lidz et al. conclude that nursing homes have many of the features of a total institution¹⁰ as described by Erving Goffman in his studies of mental hospitals, military training camps, and other organizations. These features include entry rituals designed to strip an individual of his private identity, anonymous group activities, uniform treatment of all patients, little individual variation in activity scheduling, frequent violations of privacy, and the acceptance of mutually hostile stereotypes by patient staff.

The authors are not optimistic that current federal and state regulations governing nursing home practices will ever do much to enhance patient autonomy. These regulations reflect the medical model bias that dominates nursing home care and leaves little room for a serious commitment to patient autonomy. They do not think that the most recent federal regulations (Omnibus Budget Reconciliation Act (OBRA 1987)) will significantly elevate the priority placed on autonomy. For instance, the OBRA 1987 requirement that patients be informed of changes in their environment or services does not provide the right to have any influence on the decisions to make changes.

In the authors' view, a serious commitment to protecting the autonomy of nursing home patients would entail a shift away from the medical model toward a model of care and support derived from what they learned in their research on the nature of care and provisions for autonomy in the residential care unit. They recommend that the following steps be taken in shifting from the medical model toward a model of care that characterizes the residential care unit analyzed in their study.

C Promote autonomy by balancing competing values.

Current policies, such as routine use of restraints, favor body care and institutional efficacy over promoting patients' autonomy. It may be that allowing patients increased autonomy will result in patients' safety being at higher risk or in a decrease in institutional efficacy.

C Shift regulatory schemes toward a greater emphasis on autonomy and quality of life. The authors point out that:

Administrators who must spend all of their time managing the completeness of nursing records cannot focus on making the lives of their charges fuller and more independent. Nursing home regulations grow out of the desire to upgrade care. However, this upgrading was based on the hospital model of care and is thus focused on maintaining sanitation and safety rather than personal independence.

Lidz et al. conclude by stating that the successful implementation of these changes will require a minor revolution in long-term care policy and practice rather than just procedural changes at the margin. It will require a much greater commitment to improving the quality of life in long-term care programs by focusing on the expansion of opportunities for the exercise of personal autonomy and redesigning our regulatory system accordingly.

CHAPTER 3

Charles Taylor: Autonomy within Horizons of Significance

Agich's ethic of complex autonomy and the analysis by Lidz et al. of constraints on personal autonomy in long-term care programs move away from the narrow focus on unfettered autonomy inherent in the ethic of procedural liberalism and toward the situated autonomy described by Taylor in his *The Ethics of Authenticity*. Earlier, I quoted Taylor (1991) in defense of autonomy as a major source of individual identity in Western societies. I now want to focus on Taylor's concept of horizons of significance that transcend the self and give meaning to the exercise of autonomy. The relationship between autonomy and horizons of significance does not lead to an ethic of paternalism. The relationship does, however, constitute a framework for an ethic of care, which is strikingly compatible with much of the work of feminist ethicists over the last several years. These ethicists have developed an ethic of care with an equal, dialectical emphasis on autonomy and dependence on others, which is, I think, the most efficacious ethical framework for the development of health and long-term care policies for the frail elderly and for assessing practice.

Taylor points out that:

. . . I can define my identity only against the background of things that matter. But to bracket out history, nature, society, the demands of solidarity, everything but what I find in myself, would be to eliminate all candidates for what matters. Only if I exist in a world in which history, or the demands of nature, or the needs of my fellow human beings, or the duties of citizenship, or the call of God, or something else of this order *matters* crucially, can I define an identity for myself that is not trivial. Authenticity is not the enemy of demands that emanate from beyond the self; it supposes such demands.

Taylor is critical of contemporary notions of individualism that place little importance on ties to others. This rejection of any obligation to others is described by Taylor as the slide to subjectivism over the course of the 20th century. This slide leaves individuals with a sense of unconstrained freedom, **A**ready to . . . to indulge in an aesthetics of the self.@

For Taylor, however, authentic life involves more than the capacity to create our own identities free of social obligations and constraints. It also, **A**requires (i) openness to horizons of significance (for otherwise the creation loses the background that can save it from insignificance)

and (ii) a self-definition in dialogue. That these demands may be in tension has to be allowed. But what must be wrong is a simple privileging of one over the other.@

In the end, however:

. . . authenticity can't, shouldn't, go all the way with self-determining freedom. It undercuts itself. Yet the temptation is understandably there. And where the tradition of authenticity falls for any other reason into anthropocentrism, the alliance easily recommends itself, become almost irresistible. That's because anthropocentrism, by abolishing all horizons of significance, threatens us with a loss of meaning and hence a trivialization of our predicament.

In a flattened world, where the horizons of meaning become fainter, the idea of self-determining freedom comes to exercise a more powerful attraction. It seems that significance can be conferred by *choice*, by making my life an exercise in freedom, even when all other sources fail. Self-determining freedom is in part the default solution of the culture of authenticity, while at the same time it is its bane, since it further intensifies anthropocentrism.

The notion of self-determining freedom is closely linked to the operations of instrumental reason, which gives us the power to achieve our freely chosen desires by manipulating people and circumstances without regard to a larger moral context. But, according to Taylor, instrumental reason and technical efficacy emerge from a moral context that values more than domination of nature, self-centeredness and the manipulation of others.

Already in the early seventeenth century, Francis Bacon criticized the traditional Aristotelian sciences for having contributed nothing to relieve the condition of mankind.= He proposed in their stead a model of science whose criterion of truth would be instrumental efficacy. You have discovered something when you can intervene to change things. Modern science is in essential continuity in this respect with Bacon. But what is important about Bacon is that he reminds us that the thrust behind this new science was not only epistemological but also moral.

Runaway extensions of instrumental reason, such as the medical practice that forgets the patient as a person, that takes no account of how the treatment relates to his or her story and thus of the determinants of hope and despair, that neglects the essential rapport between cure-giver and patient— all these have to be resisted in the name of the moral background in benevolence that justifies these applications of instrumental reason themselves. If we come to understand why technology is important here in the first place, then it will of itself be limited and enframed by an ethic of caring.

Benner (1994), in commenting on Taylor's work, shows how an ethic of care informs and guides the practice of nursing. I think she also shows implicitly that an ethic of care has special relevance for the care of the frail elderly. Her description of nursing as guided by an ethic of care echoes Agich's emphasis on atonement to the elder@in a caregiving relationship. Recognition and response to the other are pervasive as nurses tell stories that depict their notions of excellence in care giving. I take this to be evidence that caring practices in nursing have not been completely colonized by an objectifying devotion to a duty to be benevolent or a technological self-understanding where the recipient of care becomes an objectified behavioral change project, except in situations that nurses themselves acknowledge as breakdown and failure.

. . . nurses talk about attending to and following the body's lead. This is a dialogue with the particular that depends on knowing the embodied patient, and proceeding with care that sets limits on dominance and control of the body that ignores bodily responses and needs. The person's bodily capacities and responses are given moral worth and considered a form of personhood and intentionality that require attention, respect and response. This ethical comportment preserves the status of the other as one who makes ethical claims for consideration when nursing therapies and care that alter the body's own adaptive and recuperative powers.

In his response to Benner, Taylor (1994) notes that following the body's lead is at odds with our technological bureaucratic culture which places little value on attunement to the other. Following the body's lead also fits:

. . . badly into the canons of acceptable articulation, which tended above all in the academic and bureaucratic worlds to favor theoretical statements in general terms, preferably experience-far-ones, purged of the heat of intense personal feeling. But to do something like following the body's lead, you have to be attuned to the patient's self-feeling and self-description, you have to be experience-near to the utmost. Moreover, the kind of judgment you are making is one which cannot be rendered anything like adequately in general rules. . . . As Benner's study shows, sometimes the best medicine is anecdotal.

. . . Benner's work centrally features stories. The stories are those of practitioners, who often clarified and empowered themselves in telling them. Then they are retold, commented on and the comments lead us to other such stories. The comments allow us to see the relevance of the stories outside of situations immediately similar to the one being related. They permit us to see the more general structures and modes of thought which are blocking us here, like the ones I gestured at in talking of technological and bureaucratic civilization, articulating itself in theory. But the comments would be much less incisive and penetrating without the stories. They help to give the stories a wider application, but the stories remain central to the enterprise.

This way of proceeding brings us close to how we really understand ourselves in our ethical lives. We are incapable, lacking insight, or in the grip of a dangerous obsession, when we try to proceed without such stories in moral thinking. This means that Benner's work has tremendous relevance not only for understanding health care but for the whole newly burgeoning domain of medical ethics.

Taylor's emphasis on narrative perspectives (stories) in these passages is similar to the life review studies approach in gerontology which shares this view of narrative accounts as the principle epistemological route to understanding how people identify the meaning and value of their lives and reveal more general structures and modes of thought through reflection. Postmodernism's more esthetic appreciation of the narrative, however, is deeply skeptical of any effort to draw generally applicable ethical lessons from autobiographical accounts and the narrative arts. Our stories may have deeply ethical significance to us, but whether they apply to the lives of others is largely indeterminate.

CHAPTER 4

Feminist Contributions to an Ethic of Care

Like Agich and Taylor, recent work in feminist ethics has moved toward the integration of substantive (care for others) and procedural (preserving autonomy and impartial standards of justice) perspectives through our ability to connect with the narrated lives of others. Tanner has noted that this effort to transcend dualism in ethics is a result of perceived inadequacies in either perspective standing alone. Tanner (1996) states:

Isolated from one another, an ethic of either care or justice has its moral dangers. Care becomes, for example, parochial and paternalistic; justice becomes inhumane, rigid, and impossible to implement. Moral vision is advanced, feminist ethicists are beginning to argue, only when both perspectives are emended, one by the other.

Dillon (1992) integrates both perspectives in her concept of *Acare respect*.[@] She notes that the Kantian notion of what makes persons matter morally (this capacity for rationally autonomous moral agency) is not the only way of conceiving persons that the philosophical literature contains a number of themes about persons and the sources of respect for them.

The themes include the following. (1) What matters about each of us is not (only) some abstract generic capacity but the fact that we are specific concrete individuals. So, respecting persons involves responding to others as the particular individuals they are. (2) It is a morally significant fact about us that we each have our own way of looking at ourselves and the world. So, respecting persons involves coming to know them in their self-defined specificity and trying to see the world from their point of view. (3) Another of our morally significant features is that we cannot be entirely independent and self-sufficient, for we have needs and wants that we cannot satisfy on our own. So, respecting persons involves more than refraining from interference; it requires caring for them in the sense of helping them to pursue their ends and to satisfy their wants and needs.

One of the most fundamental criticisms of an ethic of justice, which emphasizes autonomy and impartial standards by feminist ethicists, is that it implicitly assumes *Athe view of nobody from nowhere*[@] in order to achieve an unbiased, rule-based approach to resolving ethical issues and assessing ethical outcomes.

By ignoring the concrete specificity of individual identity for purposes of moral reflection, an ethic of justice assumes that people are so like one another that any genuine plurality of selves disappears, and with that loss a reversibility of perspectives becomes incoherent. The requisite

attention to particularities of identity, itself associated with a perspective of care, demands, moreover, the contextual and narrative forms of understanding that are also ingredient in a care ethic. **A**lf the others I need to understand really are actual others . . . they require of me an understanding of their/our story in its concrete detail@ (Walker 1993).

According to an ethic of care, the self is inevitably situated and constituted by relations with others (often relations of a close personal nature); an impartiality that abstracts from all this concrete relational specificity is therefore not really possible. . . . Feminist ethicists replace these ineffective or inappropriate strategies for ensuring impartiality with an open dialogue in which all bring their own highly situated particularities of perspective and concern into a public forum for mutual critique.

Feminist ethicists do not completely dismiss the role of rules and the recognition of rights in the theory and practice of ethics. Manning (1992) points out that:

In a world infamous for its lack of caring, we need tools of persuasion to protect the helpless. This is one of the roles that rules and rights fill. We can reason in the language of rules with those who lack a sufficient degree of caring. If their natural sympathies are not engaged by the presence of suffering, we can attempt to appeal to reason: >How would you feel if you were in their place?< >What would be the consequence of such behavior on a large scale?<

She believes that rules should provide a minimum standard for morality and that rights can provide a minimum of protection for the vulnerable **A**in the face of large-scale selfishness and inattention.@

According to this perspective, autonomy, conceived as radical independence in an ethic of justice, is hopelessly abstract and fundamentally irrational in light of experience. Individuals are constituted through relations with others. On the other hand:

Most feminist ethicists do not, however, repudiate the value of autonomy insofar as it means freedom from coercion and constraint, some control over one's life, and opportunities to develop one's capacitiesCthings commonly denied to women in an oppressive society. Bringing these ideals of autonomy together with a relational ontology, feminist ethicists highlight the way in which people are dependent upon one another if they are to actualize their potentialCgone is the ideal of the **A**self-made man.@

The concept of individual rights, one of the pillars of an ethic of justice, is also revised by focusing on the relational context. An ethic of care requires more than the negative rights (rights to be left alone, free of interference) frequently associated with an ethic of justice and its emphasis on unfettered autonomy. An ethic of care also requires recognition of welfare (positive) rights which are dependent on the nurture of others, individually and collectively, in the pursuit of social goods like universal health care and economic well-being. These goods cannot be achieved without the help of others. According to an ethic of care, negative individual rights are largely supplemental rights that help facilitate the pursuit of the more fundamental welfare rights.

In an ethic of care, cooperation emerging from a relational context replaces an ethic of justice focused on the regulation of **A**antagonism among the self-interested,@by recognizing:

. . . the valid claims to attention one party may make on others: they construct social relations by determining what one party must do for others (Minow 1990). . . . One also presumes that autonomy, understood as the ability to think for oneself and develop one's capacities, is the result rather than the presupposition of the rights one has; autonomy is what one has a right to expect that others will nurture in one.

These feminist perspectives on autonomy and individual rights lead to a revision of the concept of justice itself; justice revised in terms of social relations and mutual obligations.

The idea of distributive justice predominant in an unreconstructed ethic of justice—that is, the sense of justice as a fair distribution of social benefits and burdens—is retained here but subordinated to this substantively defined account of justice in terms of social relations that are the opposite of exploitative, dominating, and oppressive.

A just society, shaped by an ethic of care which situates autonomy in a communal context, nurtures its members by creating conditions designed to help members meet their needs and pursue their desires. Such a society would be characterized by:

. . . mutual aid in which care-giving and care-receiving are reciprocal; the social structures of a just society ensure that both the benefits of care-receiving and the burdens of care-giving are shared equitably among its members.

According to Joan Tronto (1994), an ethic of care should consist of at least four component concepts based on the elements of care which she identifies as:

. . . caring about, noticing the need to care in the first place; taking care of, assuming responsibility for care; care-giving, the actual work of care that needs to be done; and care-receiving, the response of that which is cared for to the care. From these four elements of care arise four ethical elements of care: attentiveness, responsibility, competence, and responsiveness.

She further defines these four concepts as follows:

Attentiveness. Since care requires the recognition of need and that there is a need that be cared about, the first moral aspect of caring is attentiveness. If we are not attentive to the needs of others, then we cannot possibly address those needs. By this standard, the ethic of care would treat ignoring others—ignorance—as a form of moral evil. We have an unparalleled capacity to know about others in complex modern societies. Yet the temptations to ignore others, to shut others out, and to focus our concerns solely upon ourselves, seem almost irresistible. Attentiveness, simply recognizing the needs of those around us, is a difficult task, and indeed, a moral achievement.

Responsibility. The difficulty of situating the notion of responsibility—in much of contemporary political theory is a good illustration of the way in which contextual moral theories differ from much contemporary moral theory. Often our responsibilities are conceived formally as the need to conform to obligations. . . . In arguing for the inclusion of care as a political and philosophical notion, I am suggesting that we are better served by focusing on a flexible notion of responsibility than we are by continuing to use obligation as the basis for understanding what people should do for each other.

Competence. The third phase of caring gives rise to the importance of competence in care-giving as a moral notion. To include competence as a part of the moral quality of care, is obviously to align this approach with moral consequentialism. Intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met. . . . making certain that the caring work is done competently must be a moral aspect of care if the adequacy of the care given is to be a measure of the success of care.

Responsiveness. Responsiveness signals an important moral problem within care: by its nature, care is concerned with conditions of vulnerability and inequality.

Caring is by its very nature a challenge to the notion that individuals are entirely autonomous and self-supporting. To be in a situation where one needs care is to be in a position of some vulnerability.

Vulnerability has serious moral consequences. Vulnerability belies the myth that we are always autonomous, and potentially equal, citizens. To assume equality among humans leaves out and ignores important dimensions of human existence. Throughout our lives, all of us go through varying degrees of dependence and independence, of autonomy and vulnerability. A political order that presumes only independence and autonomy as the nature of human life thereby misses a great deal of human experience, and must somehow hide this point elsewhere. For example, such an order must rigidly separate public and private life.

Tronto thinks that these concepts have application beyond the immediate objects of our care and can be used to articulate needs and interests more broadly. She proposes that they be used as framework for political action and the formulation of public policy. She writes that:

The promising scenario of a politics of care, then, requires that we think about care in its broadest possible public framework. It requires that care's focus on needs change the content of our public discussion so that we talk about the needs of all humans, not just those who are already sufficiently powerful to make their needs felt. It requires a recommitment to democratic processes, for example, to listening and to including care-receivers in determining the processes of care. It requires a hard look at questions of justice, as we determine which needs to meet. And it requires, on the most profound level, that we rethink questions of autonomy and otherness, what it means to be a self-sufficient actor, and so forth.

Many feminist ethicists claim that we do not diminish the importance of justice by giving a notion of care equal status in a theory of ethics that recognizes the value of the contingent as well as the universal and the emotional as well as the rational features of human existence.

These revisions in an ethic of justice and, in our concept of a just society, are not trivial. Acceptance of these revisions would require qualitative changes in the conduct of day-to-day life and in our public policies. As Tronto has pointed out:

Care's absence from our core social and political values reflects many choices our society has made about what to honor. These choices, starting as far away as our conceptions of moral boundaries, operate to exclude the activities and concerns of care from a central place. Through that exclusion, those who are powerful are able to demand that others care for them, and they have been able to maintain their positions of power and privilege.

Care is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society. Care is a central concern of human life. It is time that we began to change our political and social institutions to reflect this truth.

CHAPTER 5

Applying an Ethic of Care to Long-Term Care Policy and Practice

Among the changes that an ethic of care would mandate, are changes in the institutions that affect our understanding and treatment of the frail elderly. Our current policies and programs for the frail elderly are not designed to protect their autonomy and the provision of basic care is far from adequate. Most publicly supported long-term care is provided in nursing homes where patient autonomy is a low priority and the quality of care is shaped by the impersonal bureaucratic routines described by Agich. In short, our treatment of the frail elderly falls far short of what we should expect under either an ethic of justice or an ethic of care. Given the current and growing emphasis on reducing public expenditures and replacing publicly administered programs with privatized alternatives, which are presumably responsive to the efficiency maximizing operations of the market, this gap threatens to widen as the huge baby boomer generation reaches their 70s in the next two-to-three decades.

In order to resist a widening of this gap, I think it would be useful to conduct a thorough critique of our perceptions of the elderly and our current policies and programs for the frail elderly from the perspective provided by an ethic of care as articulated in the work of Moody, Agich, Taylor and the feminist ethicists reviewed in this paper. Such a critique could help dispel the notion that we are doing the best we can now for the elderly in need of long-term care and the emerging assumption that in the future we will probably have no choice but to do less.

An ethic-of-care-based critique could be used as part of a broader political effort to convince the public that our capacity to resolve policy issues related to health care and long-term care for the frail elderly without the means to provide fully for themselves will be affected by more than economics. There is a moral matter at stake in how we perceive and address these issues. A moral matter that is not easy to articulate in a society where the source of value is increasingly limited to market transactions (i.e., value as determined by what sells), but that an ethic of care used to critique current attitudes, policies and practices could help bring to full expression.

The perspective generated by the kind of critique suggested here can guide us in finding ways of valuing the old outside of a purely productionist framework dominated by an obsession with technique and instrumental reason. There must be room in our view of life for wisdom and generosity derived from a recognition of mutual dependency and what those who go before us have to teach us about our own humanity and in whose lives we see what awaits us. I think this recognition and instruction can only occur in the context of an ethic based on more than individual autonomy and material gain. It requires an ethic of care that binds the generations, encourages sacrifice and generates spiritual meaning.

An ethic of long-term care based on the work discussed in this essay would recognize the need to balance the protection of autonomy with the realities of dependency and interdependency in the provision of long-term care for the frail elderly. A critique of our current long-term care system from the perspective of an ethic of care which incorporates Agich's concept of complex autonomy and a commitment to what Hofland (1995) calls the *Right to flourish*, would discover, at a minimum, that the current system is not designed to accommodate a wide range of dependency and to maximize autonomy. Such a critique would also, I think, support the four findings of the Retirement Research Foundation's project on personal autonomy in long-term care initiative.

The first of the four major findings from the project was that:

. . . personal autonomy is seriously and unduly restricted in many long-term care facilities. Most nursing home residents report that they value autonomy highly and want more control over everyday aspects of their lives and care including their personal space, room, and day-to-day lifestyle. Both professional and paraprofessional staff members agree that it is important for residents to exercise control over everyday matters, but staff members sometimes doubt that it is possible in the present regulatory and reimbursement environment.

Rosalie Kane (1995) has described a number of steps that could be taken through the regulatory process to enhance rather than restrict the autonomy of persons in long-term care facilities. She notes that:

Expectations embodied in regulations that require residents or their agents to have the opportunity to participate in their care plans have the potential to enhance autonomy. Such provisions offer residents a chance to provide input into and question the care plan. On a systemic level, regulations requiring resident councils, requiring mechanisms for appeal of care decisions, requiring the residents be consulted on room or roommate changes all have the potential effect of increasing residents' voices and power within the facility.

Other autonomy enhancing regulations include requiring that residents be:

Permitted to initiate telephone calls to primary care physicians and specialists; able to speak to their doctors alone; permitted to wear their own clothing, which could be laundered according to their instructions; residents offered choices of food; allowed access to telephone to make personal calls in private; and to choose bedtimes and rising times and be offered a snack on rising.

Perhaps the most controversial way that regulation can enhance autonomy is by mandating minimal requirements for privacy and dignity of the environment. Arguably, such standards are needed for anyone to exercise autonomy when unrelated adults live together in a group situation.

Second, there is often a substantial mismatch between resident and staff perceptions. Long-term care facility staff members often make paternalistic statements, such as, "I know what my residents like and want," but actually they often do not know. Kane and her colleagues (1990b) found that nurses, aides and residents differed considerably in how each group ranked which aspects of day-to-day life were most important for residents to control. The two items rated highly by most residents were trips out of the facility and use of the telephone, whereas nursing assistants most frequently rated organized facility activities, such as bingo and arts and crafts, as important and least frequently rated using the telephone as important. (Hofland, 1995)

Third, procedures to assess decisional capacity are seriously flawed and often biased against the elderly. Decisional capacity is frequently treated as a global, all-or-nothing phenomenon rather than as specific to a particular decision. Capacity can fluctuate with anxiety, depression, grief, or a short-term confusional state. Too often, assumptions of incapacity and actual legal determinations of incompetence result from the mere presence of advanced age, frailty, poor health, eccentricities, or a medical diagnosis, such as Alzheimer's disease or a related dementia. Moreover, once an older person is labeled as incapacitated or a guardianship has been instated, staff often wrongly assumes that the person is incapable of making any choices or decisions. (Hofland, 1995)

And fourth, although nursing assistants provide the bulk of direct care in facilities and are critical for support of resident autonomy, their task-oriented work approach greatly limits opportunities for the exercise of autonomy. Aides usually see their work as implementing routines for such tasks as lifting, turning, dressing, feeding, waking, communication between aides and residents. (Hofland, 1995)

Kane (1995) suggests several solutions to this dehumanizing situation including:

Initial and continuing education and training for aides that includes discussions of enhancement of resident autonomy in their everyday work would be a good starting point. Also important are the involvement of aides in the development of care plans, modeling of appropriate behavior by senior and professional staff, and assignment of aides to specific residents so that the aides come to know, care about, and feel responsible for these residents. Most important, autonomy must become a central goal of care, and autonomy-enhancing efforts must be rewarded through regulatory and reimbursement mechanisms.

We have only begun to tap the potential of programs designed to accommodate 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 (assisted-living) alternatives to institutional care can provide opportunities for autonomy far beyond those currently available. This is true even for those who

are seriously disabled, including persons with Alzheimer's disease who should not be limited to locked units in congregate settings, but should be provided space in which to wander.

Until we are able to handle the reality of dependency and recognize the fact that dependency does not end the need for autonomy, we are likely to remain uncomfortable with or even frightened by the aging process. Increased economic security and improved health care notwithstanding, old age could easily represent more of a threat to the baby-boomer generation than to those of the past.

Cultural norms that almost exclusively value youth (the appearance of), physical health, emotional and physical independence, and the ability to shift identities and moral perspectives in response to changes in the cultural currency (what sells) are not designed to help one live well in old age. In this cultural context, significant increases in physical or cognitive dependency will all too frequently require that a frail elderly person pay what Agich calls the full price of independence in order to receive any help with his or her disabilities. It is as if the individual must accept a downward shift in his or her status as a human being, from fully independent and autonomous to dependent and thus without the need to exercise choice or to continue activities, however limited, that are consistent with the sense of self. The individual becomes a permanent occupant of the sick role.

The validity of this perspective is confirmed, I believe by the configuration of our long-term care system that is dominated by nursing home care. In order to accommodate Agich's concept of complex autonomy, we would need to build 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.

In my judgement, an ethic of care of the kind described here, which incorporates rules derived from a concept of justice, can play an important role in the emerging debate about the ethics of managed care as efforts are undertaken at the national and state levels to expand the number of Medicare recipients and frail elderly receiving Medicaid-funded long-term care services in health maintenance organizations and other managed care arrangements. Managed care has the capacity to improve the quality and availability of care for the frail elderly through the integration of services, reduced out-of-pocket costs and increased training in geriatrics. I doubt, however, that these benefits will be achieved without a full-scale debate over the ethics of managed care, which are at least as important as the economics of managed care. Moreover, a debate based on an ethic of justice alone will not be sufficient to address all of the ethical issues posed by managed care.

A full-scale debate would include an ethic of care perspective and the generation of ethical criteria based on the concepts and concerns developed by Moody, Agich, Taylor, Tronto and others who are attempting to construct an ethic informed by notions of human need and substantive values like compassion and generosity. Decision-making procedures alone do not show us what is worth making decisions about: procedures, yes; but goals, some notion of the substantively valuable as well.

A P P E N D I X

The American Society on Aging's 40th Annual Meeting March 19-22, 1994, San Francisco.

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

Moderated by:

Monsignor Charles Fahey, Senior Associate
Maria Ward Doty Professor of Aging Studies
Third Age Center, Fordham University

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 from each to the other.

Harry Rick Moody, Acting Director at the Brookdale Center in New York City. Provocateur and leader in philosophical considerations in the field of aging.

Larry Polivka, Director of the Florida Policy Exchange Center on Aging in Tampa, Florida.

Polivka: This is really a privilege for me to have a chance to engage with Dr. Moody on this issue. It's one that is fairly new to me. I enjoyed my philosophy courses in undergraduate school 25 or 30 years ago, but for the last 20 plus years I have been involved, as I'm sure many of you are involved now, in very practical issues related to politics and policy in health, aging and other public-policy areas. Half of those as an appointee in the Governor's office in Florida where you don't have a lot of discussions about philosophy and ethics.

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 Center. It has become increasingly clear to me that we can't live by economics and cost-effectiveness analysis alone when it comes to thinking about programs for older people, when it comes to thinking about what kind of policy we want in long-term care. We need to begin to think also about what is right.

How do we determine what is right in the area of policy for the elderly? It's not just that this has become a recent concern for me. In the '70s one of the areas that I worked in was developmental services. One of the things that struck me early was how much of a moral commitment there was 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 like normalization of life for retarded people, much of it based on a rigorous commitment to autonomy, or to efforts to achieve the conditions that would make it possible for retarded people to be autonomous, to exercise as much freedom as they possibly could. One of the things that has become apparent to me in the last few years since I've been dealing more specifically with aging is that I don't think we have a model that is nearly as dedicated or committed to the autonomy principle in aging as I experienced when I was working with the developmentally disabled community back in the '70s. And as far as I can tell, that still is the reigning paradigm in the developmental disabilities community. That is, a really deep commitment to autonomy.

I think what Rick 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 to long-term care most especially, in that this has led to a kind of neglect of the client. What we really need to move toward is a greater emphasis on what he 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 of the social theorist, Jurgen Habermas, and his notion of communicative ethics.

He also offers as an alternative to the autonomy principle, something called the virtues model of ethics which places emphasis on virtues like courage, compassion and wisdom. He concludes that autonomy should not be elevated over communal relations, and an emphasis on negotiated consent that the realities of dependency, particularly in institutional settings, including nursing homes, require that much 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 this puts us in the position of risking the slippery-slope problem.

It seems to me that our biggest problem is not so much an excessive emphasis on autonomy but not enough. That 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, mainly because of the fiscal crises that the states have had to deal with. They have been cutting back on general revenue programs and have to protect the entitlement programs under the federal government and that includes nursing homes that are Medicaid funded. 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. If you look across the states, what you'll find is that 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 that you would expect if we were suffering from what would be considered an excessive emphasis on autonomy.

Let me conclude this part by describing what I think a compelling vision for long-term care reform would be from an ethical perspective. And I'm going to put the emphasis on the autonomy principle. I think that it would include features of all three models that Rick talks about, both the autonomy and rights model, the communicative ethics and negotiated consent model, and the virtues model. An integrated model which gives first place, however, to autonomy 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.

That is now largely 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 hard, 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 90 percent of all public funding for long-term care and they are a necessary part of any long-term care continuum. They do not offer, however, the most favorable environment for undistorted communication, which is an important part of Rick's concept of negotiated consent. They do not offer a good environment for undistorted communication and fully negotiated consent. An integrated moral vision which assigns first place to the autonomy principle could play a critical role in creating a long-term care system better designed to meet their needs and insure their rights.

MOODY: Autonomy sounds great in theory, but practice is something else again. Autonomy betrays the life world, the phenomenological experience of people of people who it's supposed to address. There are fundamental conflicts between autonomy and justice which are historically situated, particularly in our situation, and I think the age of autonomy is over in a sense. 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 idea, 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 so difficult that only the wisdom of Solomon can lead us to a solution. Mildred Solomon published an article last year in the *Journal of Public Health*. It blows the whistle on this stuff because what she and colleagues did was to go out, interview, do research and discover that huge majorities of practitioners—doctors, nurses, social workers in hospitals—don't buy the idea that we can collapse ethical distinctions like between withdrawing and withholding treatment. They think those are radically different, although ethicists say no. They are really morally the same; and, furthermore, they don't buy most of the language of autonomy. They acknowledge having routinely violated patients' preferences and consents 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. But one can say, no, we need to redouble our efforts because the practitioners still don't get it. They don't think the way we right-thinking bioethics people do. The trouble with that is families don't think that way either, and if you don't believe me, look at the video tapes of a conference called, "The Birth of Bioethics," and the video tapes from a conference held in Minnesota last year that brought together all the families, such as the Crusan and Quinlin families, to talk for a couple of days about their lived experiences; and 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 and I do not want to be misunderstood as a defender of nursing home status quo or of medical paternalism or imperialism. Those families were saying something very important and there have been real gains in terms of our case law and ethics.

Nevertheless, the language of autonomy does not capture their lived experiences at all. It captures, in my view, the discourse of an elite group just like in economic development. The elites are talking up here and the people in the third world are talking a different language and development will never happen unless those languages get together, unless theory and practice match each other. The lived experiences of patients and residents is very different.

Autonomy and justice clash. Even the Georgetown Mantra recognizes that justice can clash with the demands of autonomy. You can't just demand anything that you want. There are many interested parties 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 home to me yesterday in the peer group meeting on ethics committees where there was a very interesting discussion about, "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 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.

It shifted from medical paternalism, which was the 2,000 year old tradition, just the day before yesterday. Literally, the 1957 Desalgo decision, was the first time in the history of law that the term informed consent is used, and it doesn't even become popular until the 60's. So the legal revolution is very recent in our society. Informed consent and autonomy doesn't have a long history at all. And the ethical idea really goes back to John Locke, Kant, and John Stewart Mill. This is important because Locke's whole concept of rights is based on distrusting the government. Distrusting the people in power. That's how this country got started. You don't trust the king, the doctor, or people who have the power. That politics of distrust is widespread today. It's one of the reasons why we have difficulty getting a health care bill passed. The problem with our ethics is the same problem that Kant had. They want to talk about philosophy but they don't want to talk about psychology.

The problem is that when you try and implement this autonomy model, the proxy feels guilty. Guilt isn't supposed to be there, but I once talked to a doctor who goes around the country promoting advanced directives and I said, "Do you have one?" He said, "No, I couldn't do it. I didn't want to put that guilt trip on my wife." This happens more often than one realizes. "Guilt, the gift that keeps on giving," Erma Bombeck said. If we neglect the psychology as Kant did, it almost invariably neglects the psychology of caregiving, the psychology of relationships; we will blow it. So my point is that, historically, in terms of where we are now, we have entered an era of allocation of resources. The autonomy model belonged to the shift from physician-centered to patient-centered. Now we've moved from patient-centered to society-centered. We need to rethink that.

Autonomy, informed consent, all these things sound good. But what happens if they write the DNR order on your chart and then the nurses don't come. Did you know that they don't come. They come less frequently. There have been studies done on this. Sure, they don't come because they have built into them the heroic model of medicine. And we can say they ought to change, they shouldn't have that model, they should come. Writing a DNR order shouldn't mean the withdrawal of attention and all the rest of it. There's a reason why minority folks are very suspicious of advanced directives. There's a reason why people from working class backgrounds are very suspicious. They haven't gotten 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, gender into account in bioethics, we will miss the boat. We will, in fact, create more inequality.

Autonomy as a developmental idea. It's easier to say no than it is to say yes, not just with regard to resources, but with regard to the self. 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 give autonomy for life and death decisions when 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 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 a virtue ethics and the others. That is not my approach. I tend to approach it in terms of communicative ethics. I think the real locus of what I have to say is that what is needed here is not an emphasis on autonomy of individuals but an emphasis on social movements—things like the Hospice movement, the natural childbirth movement, which are examples that actually changed the practice of health care—because we were not approaching it as individuals seeking our rights, but rather seeking to transform the nature of practice. Until we do that, I think, we will be fearful like explorers in the days of Columbus. So people who have been brainwashed into this autonomy model think that once you give up the language of rights, there will be nothing left to protect people. And that's the problem, we need a new cognitive map, a new way of mapping the moral discourse. The space of moral communication as Margaret Urban Walker calls it. What we're really talking about is creating spaces for communication.

In our secular society, bioethics represents that elite secular humanist trip shared by a small group, but not necessarily by masses of people and their lived experiences. We need to remember that there's a profound religious dimension to this discourse. When I was talking to my friend, Ron Mannheimer, this morning and my roommate here, I said, "What am I going to say about autonomy?" He said, "Mention Kierkegaard." He said, "We don't give birth to ourselves. We don't own ourselves. Life is a gift." Therefore, the aim maybe shouldn't be self possession but self surrender. Not everybody agrees with the religious perspectives. This is a pluralist society, you don't need to buy into that. But buy into this at least—what people want is not autonomy, but dignity and respect. We need to find ways to give them that dignity and respect even when they're not in a position, because maybe they never have been in the position in their whole life of exercising self determination, for material reasons, psychological reasons, all kinds of reasons. They still need dignity, they still need 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.

Polivka: Rick 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 practically last about the potential autonomy of the very disabled people. As a matter of fact, if you look at the two institutions in Florida that have been closed in the last 25 years, they 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, were not in any way cognitively aware, are now doing many self-initiated things with training and support. That whole effort, the rationale for closing those two institutions, was that these people that were flat on their backs, 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 elderly who are seriously impaired. And our original notion was that this would be a program that would provide privacy, a home-like setting, 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 this person we're 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. It will simply slip out of sight and what I referred to earlier as the slippery slope toward paternalism and professional domination will occur.

Moody: Much of what you say goes back to a basic analogy between aging and other groups: the physically disabled; the mentally retarded; 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 and ask ourselves what are the differences between the life plans and the life world of the young or disabled as opposed to older people, frail people, home care. If we don't take that 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 disabled and the frail elderly.

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

You 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 are not just dehumanized, oppressive types of places. They may create conditions for community. We need to look at the best practices and the best model.

Negotiation. You use the word slippery slope, but in your examples you acknowledged that there would already be trade-offs between autonomy and other goods, 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 a negotiation?

Rationing. The health care reform deliberations in Washington are where we do run into the issue of justice versus restricting individual preferences. I think 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 it as such.

Father Fahey: Cohen did a study of two different models of home care, one which would basically be an agency model in which, as traditionally, the agency would be the gatekeeper and also would sort of be the case manager. The other being a vender type of model in which the disabled person was given resources and minimal supervision, was able to hire and so on. In talking about his research, Alias said something that has remained with me and helped influence my own thinking and I think it falls somewhere in between, or perhaps would be agreed to by both. He says, "You folks in many ways have been inadequate in your advocacy of autonomy because least restrictive settings isn't the answer."

In fact, the motto of Citizens for the Retarded has not been autonomy, its been, "This is the Time to Flourish." And that 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 is integral to its national health reform. The title of the work was, "A Time to be Old, A Time to Flourish." And it was a kind of notion of, hey autonomy is okay, but its got to 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.

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, 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 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 vs. the elderly, I think that we're in danger of making agist 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 when you're developing public policy.

Moody: I don't think people go to nursing homes because they want to. But 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. And how that might be the same or different with regard to the younger disabled, the frail older folks and the role of community there. I do agree very much with your observation about the culture of disability and the creation of communities that are empowered who, in turn, challenge the professionals and say wait a minute. We are younger people, but we are speaking on behalf of the older ones. We wouldn't accept that kind of dialectic with regard to the women's movement the 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 profession of aging. So we haven't got that kind of mobilization of the life world as we do with the disabled; it doesn't exist.

Instead, we have what Carol Estes calls the aging enterprise. That's us. I don't say that to indict us; I make my living in this business. I say that simply to bring it to consciousness so we realize the paradoxical aspect of our situation.

Audience: I'm still having a problem in terms of definitions. Things like respecting their dignity, and that 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.

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, **A** 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 Rick was just saying, that 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, or can be made 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.

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

From a political point of view, you have a weakness when you're arguing a cause on a cost benefit strategy, because that's the kind of utilitarian argument the facts can always prove you're wrong. That's why principle-based claims are better in a sense, but also sometimes more divisive. They need what Plato would call a *mythos* to go along with the *logos*. So you can sell nursing homes without walls, dignity and all that because people can relate to that and respond to it.

We in our culture prize autonomy because we believe that's the way that we respect people. That's the way we take account of them as moral personalities to use Kant's terms. It is exceedingly

important for practitioners not to be brain washed by this language because there are many situations where we disrespect people and act in an undignified way to them that has nothing to do with the choices they make. It has to do with the way that we talk to them. The way that we are with them. In other cultures where people don't have a lot of choices, they may yet have a kind of dignity from their position, from their status, from their role in life and so forth. In many situations we don't have that for older people in society. So we say, "Well they don't have any dignity. We've got to give them more choices." They may be unable to act on those choices, or we can't collect enough revenue (taxes). And that's the problem because that interferes with people's autonomy. I worry about autonomy because too many people buy into it and will feel that's the reason for rejecting the taxes that would achieve the goals that you want and by the way that I want.

Audience: How applicable is the notion of autonomy in the development of policies and programs for those with Alzheimers

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, although 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 judgement 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 Alzheimers, 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 Alzheimers 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 is that 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 Koon 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 dependency is okay. 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: Interdependence, 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.

Moody: Negotiation is a much misunderstood term and a lot of people think of it as power. You win, I lose. But real negotiation involves trying to understand the point of view of the other. More deeply is an internal negotiation that I negotiate with myself, and that's what you were alluding to in terms of we can't maximize all values. So that when we negotiate with people, whether it's in a marriage or a business situation, at its best it is an invitation in the communicative sense for me to reflect on what I really care about and what am I willing to give up some of, and that process can be emancipatory, hopefully. But it doesn't always happen that way.

Father Fahey: I can't help but reflect about something I heard at the Gerontological Society a year or so ago. Paul Faultus, distinguished university of Berlin psychologist, speaks this way of how do you 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's 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. If I may 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 stake holders, all of whom 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 and pay in sharing risks broadly, particularly those who are most vulnerable at any age and who are not part of the production system.

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