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Charles W. Lidz

Robert M. Arnold

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Rethinking Autonomy in Long Term Care

CHARLES W. LIDZ
ROBERT M. ARNOLD*

I. INTRODUCTION	603
A. <i>The Central Role of Autonomy in Bioethics</i>	604
II. THE AMBIGUITY OF AUTONOMY	606
III. THREE MODELS OF AUTONOMY	608
A. <i>Total Independence</i>	608
B. <i>Autonomy as Free Action</i>	609
C. <i>Autonomy as Effective Deliberation</i>	612
IV. AUTONOMY AND THE "TOTAL INSTITUTION"	614
V. AUTONOMY: CITY-STATES AND INDIVIDUALS	616
VI. EXTENDING AUTONOMY BEYOND DECISIONMAKING	617
VII. AUTONOMY AS CONSISTENCY	618
VIII. CONCLUSION	623

I. INTRODUCTION

In a symposium on Competency and the Law, a paper on the ethics of autonomy in long-term care may seem out of place. Certainly, there is no immediate connection between the ethical issues in the organization of nursing homes and the legal issue of competency. Yet, competency is a central concept with important implications for issues such as informed consent, decisions to terminate life supports, or surrogate decisionmaking.¹ The legal and ethical dictum that competent patients should be allowed to make health care decisions for themselves reveals the close connection between competency and autonomous decisionmaking.²

We would like to suggest that, at least in some settings, focusing solely on decisionmaking is not optimal if one wishes to promote patient autonomy. We will argue that the traditional model of

* We wish to thank Lynn Fischer for her work on the larger project and George Agich and Lissa Wettick for their thoughtful comments on different drafts. The work for this Article was partially supported by a grant from the Retirement Research Foundation. Parts of this Article are also contained in our book, *THE EROSION OF AUTONOMY IN LONG-TERM CARE* (1992).

1. PAUL S. APPELBAUM ET AL., *INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE* (1987); TOM L. BEAUCHAMP & JAMES L. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (1979); DAN W. BROCK & ALLEN E. BUCHANAN, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* (1989); Loren H. Roth et al., *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279 (1977).

2. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *MAKING HEALTH CARE DECISIONS 20* (1982) [hereinafter PRESIDENT'S COMMISSION].

informed consent is largely irrelevant to the promotion of autonomy in the daily lives of elderly patients. This suggests that traditional conceptions of competency, which are invariably tied to decisionmaking, should play a much less central role in the law and ethics of autonomy, at least in the nursing home setting.³ Instead of focusing on decisionmaking, we will argue that more attention needs to be paid to an alternative conception of autonomy, autonomy as consistency, and to the institutional factors that promote elderly persons' abilities to engage in activities consistent with their commitments, values and life plans. We hope this Article will prompt policy analysts to re-examine how policy and legal reforms affect the autonomy of elderly patients who live in institutions.

A. *The Central Role of Autonomy in Bioethics*

In the last two decades, a new value, which largely overshadows concern with other issues, has been introduced into the discussion of health care law and ethics—patient autonomy.⁴ In contrast to older legal and ethical models of health care, which emphasize the prevention of malpractice and physicians' obligation to provide the correct and needed treatment, the new autonomy-based model requires health care providers to focus on implementing the patients' decisions. The ethical task of the health care provider changes from an obligation to determine what is objectively best for the patient to determining what the patient wants.

Seeking the patient's permission prior to instituting treatment promotes the patient's autonomy by treating a decision about the therapeutic plan as, ultimately, the choice of the patient and not of the physician. The opinion in *Nathanson v. Kline* eloquently states the connection to autonomy:

Anglo-American law starts with the premise of thorough going self-determination. It follows that each man [sic] is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life saving surgery, or other medical treatment. A doctor may well believe that an operation or other form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the

3. Since many, maybe most, long-term nursing home residents have substantially diminished cognitive capacity, a focus on decisionmaking autonomy suggests that autonomy is irrelevant to most long-term nursing home settings for the elderly. One virtue of our model is that it is not as restrictive as a competency-based model of autonomy.

4. Caroline Whitbeck, *Why the Attention to Paternalism in Medical Ethics*, 10 J. HEALTH POL. POL'Y & L. 184, 181-84 (1985).

patient⁵

Like most arguments in law and ethics, support for decisionmaking autonomy in health care is justified both consequentially and deontologically.⁶ First, respecting an autonomous decision is valued for its likely consequences. Contrary to the conception of well-being found in the Hippocratic Oath, allowing people to select their own treatment maximizes patients' best interests.⁷ This is the traditional liberal argument that individuals are better judges of their own interests than even the most benevolent others.⁸ Best interest is seen not as an objectively determined, unified notion but as definable only in the context of a particular person's goals and values. A particular professional's concept of health is not always in the patient's best interests. Individuals may feel that striving for health is not as important as staying comfortable or spending time engaged in other pursuits. Even when the importance of promoting health is undisputed, a variety of approaches may be available, depending on the individual's non-medical goals. Given the subjective nature of "best interest," most supporters of autonomous decisionmaking argue that those whose interests are at stake are best qualified to determine the proper goals of medical therapy.

However, it is often argued that the reasons for respecting autonomy transcend its instrumental value.⁹ Even assuming that the patient is competent, there are many situations in which an outside expert might make better decisions than a patient concerning the patient's best interest. Yet, some deontologists would argue, even in these situations, autonomous decisionmaking by the patient is preferable. It is intrinsically good to allow individuals to direct their own lives.¹⁰

Subjectively, one experiences this sense of autonomy as not wanting to be "pushed around," "manipulated," or "deceived." One desires to define values and decide how to act to achieve goals even if these decisions are sometimes incorrect. This value is deeply ingrained in cultural ideals throughout the western world,¹¹ particularly in the United States.¹² There is a growing agreement among

5. *Nathanson v. Kline*, 350 P.2d 1093, 1104 (1960).

6. See BEAUCHAMP & CHILDRESS, *supra* note 1, at 55-56.

7. *Id.* at 60-61.

8. JOHN S. MILL, ON LIBERTY 93 (C. Shields ed., 1956).

9. GERALD DWORKIN, THE THEORY AND PRACTICE OF AUTONOMY 22-23 (1989).

10. KANT ON THE FOUNDATION OF MORALITY 163-65 (Brendan E.A. Liddell trans., 1970).

11. EMILE DURKHEIM, THE DIVISION OF LABOR IN SOCIETY 407-08 (George Simpson trans., 1964).

12. ALEXIS DE TOCQUEVILLE, DEMOCRACY IN AMERICA 129-33 (1945).

medical ethicists and many practicing physicians that autonomous patient decisionmaking is an important part of health care.

II. THE AMBIGUITY OF AUTONOMY

Although it may be clear why autonomy is important in making health care decisions, it is far from clear what the term means. Autonomy is derived from the Greek *autos* (self) and *nomos* (rule or governance or law), and was first used to refer to self-rule in Greek city-states. Political autonomy for the Greek city-states was, perhaps, as important to the Greeks as personal autonomy is to Americans. We will return to this concept because the analogy to the independence of a political entity is very helpful in thinking about aspects of personal autonomy that have been largely overlooked in the medical ethics literature.

Perhaps because the concept of autonomy has departed so far from its origins, the concept as used in ethics is far from clear. Its ambiguity is reflected in the diversity of definitions found among leading authorities. For example, the President's Commission defines autonomy or self-determination as "an individual's exercise of the capacity to form, revise and pursue personal plans for life";¹³ Beauchamp and Childress define autonomy as "being one's own person, without constraint either by another's action or by psychological or physical limitations";¹⁴ J.L. Lucas says "I, and I alone, am ultimately responsible for the decisions I make and am in that sense autonomous";¹⁵ while recent theorists such as Gerald Dworkin and George Agich have characterized autonomy as the ability to identify with the decisions that one makes.¹⁶ Other theorists, such as Collopy and Thomasma, define autonomy not as a unitary concept but as a group of related notions.¹⁷ It is apparent that autonomy is being used in a very broad and ambiguous manner. As Gerald Dworkin points out:

It is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obliga-

13. See PRESIDENT'S COMMISSION, *supra* note 2, at 44.

14. See BEAUCHAMP & CHILDRESS, *supra* note 1, at 59.

15. J.R. LUCAS, PRINCIPLES OF POLITICS 101 (1966).

16. See GEORGE J. AGICH, AUTONOMY AND LONG-TERM CARE (forthcoming 1994); DWORKIN, *supra* note 9, at 6.

17. See Bart J. Collopy, *Autonomy in Long-Term Care: Some Crucial Distinctions*, 28 GERONTOLOGIST 10 (1988); David C. Thomasma, *Beyond Medical Paternalism and Patient Autonomy: A Model of Physician Conscience for the Physician-Patient Relationship*, 98 ANNALS INTERNAL MED. 243 (1983).

tion, with absence of external causation, with knowledge of one's own interests. It is even equated by some economists with the impossibility of interpersonal comparisons. It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles. About the only features held constant from one author to another are that autonomy is a feature of persons and that it is a desirable quality to have.¹⁸

Concerns with clarity of definition may simply be a fixation of philosophers and other academics. What difference does it really make, to either law or practice, whether or not we have a clear definition? The answer is that what we do to honor an individual's autonomy is determined by our definition of it. If autonomy means dignity, then what we do to honor the individual's autonomy is quite different than if it means self-knowledge.

In assessing different concepts of autonomy, one needs to be aware that scholars have defined autonomy for various purposes.¹⁹ Some have defined autonomy for the purpose of exploring different systems of governance. In health care law and ethics, conceptions of autonomy are typically used to delineate patients' rights to make health care decisions for themselves. The definitions of autonomy are used to determine who can make such decisions (competence) and what health care professionals must do to respect autonomy (informed consent).

Our interest in autonomy is somewhat different. We have been concerned with how long-term care institutions for the elderly can be structured so as to maximize their inhabitants' autonomy. For reasons that will become clear shortly, this concern turned our focus away from models of autonomy that centered around discrete decisionmaking and toward a model that looked at the relationship between patients' lives and their goals and commitments. This, in turn, has caused us to consider the autonomy-promoting effect of an entire system of care as opposed to a single discussion between professional and patient. Thus, we concentrate on facets of autonomy that are different from those of most theorists who have been concerned with acute care issues.²⁰ In order to understand better the problems involved, we undertook a participant observation study of long-term

18. See DWORKIN, *supra* note 9, at 6.

19. THE INNER CITADEL: ESSAYS ON INDIVIDUAL AUTONOMY 5-6 (John Christman ed., 1989).

20. For others with similar concerns, see AGICH, *supra* note 16; Harry R. Moody, *From Informed Consent to Negotiated Consent*, 28 GERONTOLOGIST 64 (1988); see also Whitbeck, *supra* note 4.

elderly care settings that have been reported elsewhere.²¹ We found that residents in the nursing home had very little autonomy of any sort. The difficulties in promoting their autonomy seemed more profound than those usually discussed in the medical ethics literature. Our goal here is to explore the ramifications for the general concept of autonomy in health care law and ethics that arise from trying to apply autonomy models to the analysis of the social institution of the nursing home. This requires a brief summary of the current models of autonomy in medical ethics.

III. THREE MODELS OF AUTONOMY

A. *Total Independence*

Many philosophers conceptualize autonomy synonymously with independence from external influences; to be autonomous means one is radically self-sufficient, dependent on no one else.²² Autonomous persons are independent, self-ruled entities who make decisions based solely on their own reasons.²³ Indeed, such a concept seems to be nothing but an elaboration of the concept of self-direction. What could be more desirable than total freedom?

Appealing and clear as such a conception of autonomy may be, it is more a mythical fantasy than a usable model of human activity. All human life takes place in a historical, social and cultural context.²⁴ Individuals' values and actions are necessarily affected by their past and environment. People do not autonomously choose their genetic background, their parents, the time period or society in which they are born or raised. All these factors place limits on the persons they are and will become, and make the notion of an independent, self-ruled person unrealistic. Dworkin summarizes this objection by stating:

If this is what moral autonomy demands, then it is impossible on both empirical and conceptual grounds. On empirical grounds this view defines our history. We are born in a given environment with a given set of biological endowments. We mature more slowly than other animals and are deeply influenced by parents, siblings, peers, culture, class, climate, school, accident, genes and the accu-

21. CHARLES W. LIDZ ET AL., *THE EROSION OF AUTONOMY IN LONG-TERM CARE* (1992).

22. See LUCAS, *supra* note 15; ROBERT P. WOLFF, IN DEFENSE OF ANARCHISM 14, 41 (1970). For a critique of this view in the philosophical literature, see AGICH, *supra* note 16; DWORKIN, *supra* note 9, at 34-47.

23. See LUCAS, *supra* note 15.

24. JOEL FEINBERG, HARM TO SELF: THE MORAL LIMITS OF CRIMINAL LAW 38-39 (1986).

mulated history of the specifics. It makes no sense to suppose we invent the moral law for ourselves than to suppose that we invent the language we speak for ourselves.²⁵

Moreover such an ideal violates Kant's categorical imperative. One cannot consistently will that everyone should behave according to such a maxim. It is impossible to imagine a society made up of such people. Peoples choices will inevitably influence others, and thus the claim of one person for such independence would interfere with another's freedom. Such a position makes it difficult to justify and enforce simple elements of socially acceptable behavior children are taught, such as sharing, "taking turns" and politeness.

Instead of equating autonomy with absolute independence, we will look at more complicated notions of autonomy, which recognize that individuals are socially and historically situated, bound together by ties of tradition and mutual obligation. Rather than asking whether one's actions were influenced by others, we will be concerned with how those influences affected one's actions and whether the influences subverted one's control, reasoning process or identification.

B. *Autonomy as Free Action*

Free action implies that the activities involved are both intentional and voluntary.²⁶ Activities are intentional if they are undertaken with a desired end that the actor believes they will facilitate. Intentional acts are not events that merely happen to people. Moreover, it is not necessary for the intended end to be realized. Many intended acts do not realize their goals. Intentional actions are also different from accidental actions. If someone mistakenly drinks a glass of arsenic instead of lemonade, it cannot be claimed that she intended to commit suicide.

The act must occur because the individual wanted to do it rather than because others forced the person to do it. But defining "force" is not easy. Faden and Beauchamp address the question by examining the polar extremes of completely voluntary and involuntary acts.²⁷ An involuntary act is one in which the person is completely dominated by an external agent. A voluntary act is one that either has not been the target of an influence attempt or, if it has been the target of such an attempt, where the attempt has been unsuccessful or did not

25. See DWORKIN, *supra* note 9, at 36.

26. Bruce L. Miller, *Autonomy and the Refusal of Lifesaving Treatment*, 11 HASTINGS CENTER REP. 22, 24 (1981).

27. RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* 258-59 (1986). For a different view, see Joel Feinberg, *Law Paternalism*, in *PATERNALISM* 1-18 (Rolf E. Sartorius ed., 1983).

deprive the actor in any way of willing what she wished to do or believe.²⁸ This definition of voluntariness does not exclude all external pressures. External influences can affect a person without rendering an action involuntary if the person acts on the basis of what she wants rather than on the basis of an external agent's will.

The problem, as Faden and Beauchamp note, is that such clear cases are rare.²⁹ Most actions fall somewhere in between the completely voluntary and involuntary extremes. A continuum exists between voluntary and involuntary acts and, correspondingly, between autonomous and non-autonomous acts. In reality, an action may be more or less influenced.

Many authors delineate three groups of external influences.³⁰ At one extreme are coercive influences.³¹ By presenting a threat of unwanted and unavoidable harm that a person will be unable to resist, the coercer gains control over another's actions. These influences render the action involuntary and hence non-autonomous. For example, threatening to tie patients into a geri-chair if they do not participate in music therapy probably renders subsequent participation involuntary. At the other extreme are persuasive influences.³² These are attempts to influence a decision by appealing to reason and, in the final analysis, they still leave the decision in the hands of the actor. A patient can, after hearing the reasons for attending music therapy, freely decide to accept or reject the persuader's line of argument. Because these influences do not control another's action, they do not impede voluntariness or autonomy.

Between these extremes lies the third group of influences, which Faden and Beauchamp define as manipulative.³³ Manipulative influences are attempts at "noncoercively altering the actual choices available to the person or [at] nonpersuasively altering the person's perceptions of those choices."³⁴ Manipulative influences have varying effects on the voluntariness of an act. There is no hard line between those manipulative influences that substantially interfere with voluntariness (and render a choice nonautonomous) and those that do not.

We have been discussing external forces that render one's actions less than fully autonomous. While it is not our primary interest here, it should be noted that forces internal to an individual may also affect

28. See FADEN & BEAUCHAMP, *supra* note 27, at 258.

29. *Id.*

30. *Id.* at 256-59.

31. *Id.* at 257.

32. *Id.* at 259.

33. See *id.* at 354-62.

34. *Id.* at 261.

the voluntariness of the individual's action.³⁵ For example, someone who is claustrophobic may want, but be unable, to step into an elevator. Addictions and severe compulsions may also control a person so completely that his or her behavior no longer reflects the person. Behavior so influenced is generally characterized as involuntary.

An example of this devotion to autonomy as free action is the law of battery, which preceded the doctrine of informed consent. The physician was obliged to refrain from "battery" (i.e. a non-consensual touching). She had an obligation to acquire the patient's consent (explicit or implicit) before performing a procedure. However, there was no need to provide any information. The requirements of the physician were completely negative. The patient was free to choose whether or not to have an operation, and the physician was obligated to honor that free choice. Recent regulations limiting the restraining of patients also seem designed to promote autonomy as free action.

There is something plausible about this conception of autonomy. It seems to explain the intuition that most of one's daily, mundane activities are, in a certain sense, autonomous. Getting out of bed in the morning or wearing black rather than brown shoes are intentional and voluntary activities. This concept also accounts for our view that most people have at least some capacity for autonomous action. The requirements for autonomy as free action are minimal. As long as one has the ability to form preferences and as long as one believes that one's actions can influence the environment in predictable ways, one has the capacity to act autonomously. Even very young children and moderately demented individuals are likely to have sufficient capacity to act autonomously, at least some of the time, according to this definition. For example, if a moderately demented patient calls out for food when hungry, there are adequate behavioral grounds for concluding, according to our definition, that this is an autonomous act.

In spite of its inherent plausibility, the above concept of autonomy is of limited use in designing institutional structures that promote autonomy in long-term care. The suggestion that autonomy can be promoted by minimizing pressures on patients is of some help. It would clearly rule out some common policies, such as restraining patients in their wheelchairs. We will discuss below some of the autonomy problems in long-term care settings, which cannot be dealt with in a free action model. However, it is worth noting here that the largely negative construct of not interfering with someone else, which is the core of autonomy as free action, is not very helpful to someone

35. John Christman, *Autonomy: A Defense of the Split-Level Self*, 25 S. J. PHIL. 181 (1987); Timothy Duggan & Bernard Gert, *Voluntary Abilities*, 4 AM. PHIL. Q. 127 (1967).

whose life is largely devoid of meaningful relationships and activities. Moreover, most such patients, if they were able to function independently with no interference from the outside, would not be living in a nursing home. A more positive conception of autonomy is needed.

C. *Autonomy as Effective Deliberation*

Effective deliberation consists of making a decision based on an adequate understanding of the situation and the possible alternative courses of action.³⁶ This sense of autonomy is distinct from autonomy as free action. A person can act voluntarily and intentionally without effectively deliberating and understanding the relevant issues. Autonomy as effective deliberation emphasizes acting based on an understanding of the situation, the action, its consequences, and possible alternatives.

This model of autonomy is most clearly enshrined in the legal concept of informed consent. In its decision in *Canterbury v. Spence*,³⁷ the D.C. Circuit spelled out the leading legal framework of informed consent. It specified that the physician should disclose to the patient all information that a reasonable person would want to know prior to making a decision, including the risks, benefits, nature, purpose of, and alternatives to, any contemplated procedure.

While some attack this model as legally far-reaching, it falls considerably short of an ethical ideal because it requires only disclosure. Truly autonomous activity requires more than simply receiving the relevant information; one must understand it. What do we mean by "understanding an act"? Faden and Beauchamp offer the following definition:

A person has a full or complete understanding of an action if there is a fully adequate apprehension of all the relevant propositions or statements (those that contribute in any way to obtaining an appreciation of the situation) "that correctly describe (1) the nature of the action and (2) the foreseeable consequences and possible outcomes that might follow as a result of performing and not performing the action."³⁸

This definition is idealistic. Most decisions are not made with perfect understanding and, thus, are not perfectly autonomous. The extent to which someone understands an action will depend on the complexity of the decision at hand, what one is told about it, what one's preconceptions were before considering the issues, one's mental

36. See Miller, *supra* note 26; FADEN & BEAUCHAMP, *supra* note 27.

37. 464 F.2d 772 (D.C. Cir. 1972).

38. See FADEN & BEAUCHAMP, *supra* note 27, at 251.

capacities at the time, the time one has to analyze the problem, and other situational variables. A decision made after careful analysis is more fully considered than a hurried decision, made with limited information and under some stress. This conception of autonomy admits of degrees. The more fully one understands one's action, the alternatives, and their consequences, and the more one makes a decision based on this information, the more autonomous the action is.

There are also different meanings of the term "understand." One meaning is that the patient can "grasp the meaning" of relevant facts.³⁹ Other conceptions of "understanding" suggest that one must appreciate the nature, significance, and implications of these facts for one's life situation.⁴⁰ For example, cancer patients sometimes consent to chemotherapy after being told, and apparently understanding, that it will make them feel sick. Later they feel that they did not make an informed decision when they experience the intensity of the side effects. The more completely people appreciate the consequences of their actions on their lives, the better they understand their situations, and thus, their decisions will more precisely meet the criteria for autonomy as effective deliberation.

Autonomy as effective deliberation, however, requires more than understanding. Effective deliberation requires that the actions that the individual proposes to take must have some likelihood of achieving the desired result. Consider, for example, an otherwise healthy 70-year-old woman who says that her primary health care goal is to live as long as possible. Imagine this woman develops breast cancer. Even if she understands the risk and benefits of a mastectomy for localized cancer, her refusal to undergo surgery because she is phobic of anesthesia would be considered ineffective because she has irrationally weighed the risks of anesthesia.

This notion of autonomy is most relevant when a person is facing a significant decision with clearly identifiable options. It is no surprise that this notion of autonomy has been most extensively relied upon with hospitalized patients in need of surgery or some other discreet procedure. In these situations, a patient is faced with a decision that has major consequences and risks the physician can describe to the patient. The patient, having acquired this information, can effectively deliberate about what, given her values, she wants to do.

This model of autonomy underlies much of the recent legislation designed to promote patient autonomy. The best example is the

39. WEBSTER'S NEW TWENTIETH CENTURY DICTIONARY 1994 (2d ed. 1979).

40. See APPELBAUM ET AL., *supra* note 1, at 85.

recent Patient Self-Determination Act.⁴¹ This bill was designed to ensure that patients are informed of their rights to refuse medical treatment and of the rule of advance directives in clinical decision-making. The law requires that all patients admitted to health care facilities and nursing homes receive this information. The underlying goal was to promote effective deliberation surrounding issues of terminal care, death and dying.

We noted earlier that our observations of nursing homes raised serious questions in our minds about the above models of autonomy. In order to clarify, we need to digress briefly and summarize some of the observations from our empirical study. This study used ethnographic methods, and a systematic computerized analysis of the field notes, to describe the life situations and routines of elderly residents of two nursing home units and an independent living residence. The results of that study should help clarify why we find the above models of autonomy ineffective for a discussion about promoting autonomy in long-term care settings.

IV. AUTONOMY AND THE "TOTAL INSTITUTION"

First, we were surprised by the lack of ethical decisions, as traditionally defined, that patients faced. During the study period we saw no problems with foregoing life support, no disputes regarding confidentiality, and no dilemmas regarding informed consent. Even disputes regarding patients' dispositions occurred more rarely than we would have guessed.

Rather than finding discrete decisions that raised ethical issues, we became increasingly concerned about the effect of the entire environment on autonomy. While no single situation was ethically problematic, we found that the cumulative effect of living in the nursing home adversely affected the patient's ability to live an active and self-directed life. As the study progressed, we became increasingly convinced that the nursing home is a type of environment that the sociologist Erving Goffman once described as a "total institution."⁴² Total institutions are people-processing organizations that involve their "inmates" in a twenty-four hour a day living and working situation that is largely cut off from the outside world. Goffman notes that:

A basic social arrangement in modern society is that the individual tends to sleep, play, and work in different places with different co-

41. Pub. L. No. 101-508, § 4751, 104 Stat. 1388-204 (1990).

42. ERVING GOFFMAN, *ASYLUMS: ESSAYS ON THE SOCIAL SITUATION OF MENTAL PATIENTS AND OTHER INMATES* 1-124 (1961).

participants, under different authorities, and without an over-all rational plan. The central features of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life⁴³

Among the different types of organizations which Goffman classifies as "total institutions" are mental hospitals, nunneries, military training camps, preparatory schools, concentration camps, orphanages and "old age homes."⁴⁴ All of these seemingly diverse institutions similarly affect individuals' lives. We believe that the nursing home we studied closely approximates Goffman's "total institution." While nursing homes do not meet every characteristic of a "total institution," they still can be classified as such. Goffman suggested that total institutions substantially undermine personal autonomy.⁴⁵ "Total institutions disrupt or defile precisely those actions that in civil society have the role of attesting to the actor and those in his presence that he has some command over his world—that he is a person with 'adult' self-determination, autonomy and freedom of action."⁴⁶

Goffman identifies two different sets of features of total institutions, both of which apply to nursing homes. These features also help explain the negative effect of nursing homes on elderly participants' autonomy. The first set of features Goffman notes involve those social processes that undercut individuals' sense of themselves as having independent and valuable identities.⁴⁷ One such process is the stripping of the individual of a private identity through such categorizing and processing of the individual's life as history taking or fingerprinting. The nursing home patients we observed had their identities reduced from people with long and complex psychosocial histories to patients who were largely known by the medicalized stories recorded in their charts. The stories were rich in medical detail but contained little about the person. Moreover, their rooms were furnished identically with hospital stock furniture. Patients were not permitted to bring identity tokens such as furniture, family photographs or other valued personal possessions to the nursing home. Autonomous identity was further weakened by an almost total lack of privacy. For instance, patients all shared rooms whose doors were continuously left open. Patients spent their entire day in the company of other patients and staff with whom they had no prior personal ties.

A second feature of total institutions that undercuts the indepen-

43. *Id.* at 5-6.

44. *Id.* at 4-5.

45. *Id.* at 13.

46. *Id.* at 43.

47. *Id.*

dence of the individual is the loss of control over routine features of their lives. For residents of the nursing home that we observed, all aspects of their lives were conducted in the same place under the direction of a single staff. Patients rarely left the nursing home, and they ate, slept, and spent their waking hours all within the same building. Patients' daily routines—their rising in the morning, mealtimes, and bedtimes—were highly scheduled by staff. The staff was responsible for maintaining a routine that insured the institution complied with regulatory requirements and which minimized staff time commitments. The staff was allowed considerable power to make wide-ranging decisions about the patients' lives. Staff-patient interactions consisted almost exclusively of patients asking staff for permission and never the reverse. Whenever there was disagreement between patients and staff, the staff's viewpoint prevailed. Patients were not included in either formal or informal decisionmaking processes.

V. AUTONOMY: CITY-STATES AND INDIVIDUALS

To understand the ramifications of such observations, let us return now, briefly, to the initial meaning of the word "autonomy." Self-governance in the Greek city-states was always a tenuous situation, but one they were intensely proud of. But of what did self-governance consist? It was essential for each city-state to have its own government with the capacity to make its own decisions. Any given political system benefits if the decisions it makes are based on a factual reading of the situations in which the polity exists. In our terms, any polity is better off if it can "effectively deliberate." But a political system that makes decisions based on an independent understanding of factual information is not the only requirement for an autonomous state to exist. Such a state requires a variety of other factors including: (1) a viable political culture with a strong sense of independent identity; (2) a sense of direction or mission about the future nature of the state, including both what it will do for its citizens and its relations with the outside world; and (3) a series of alliances and external supports which provide both a sense of protection from hostile forces and economic trading connections.

This is not a novel analysis. Similar observations are found in Greek political philosophy and modern political science. What we are suggesting is that the requirements for the autonomy of a political entity are a helpful analogy for thinking about the autonomy of patients in nursing homes. The analogy suggests that one needs to think about a variety of issues underplayed in the medical ethics literature on autonomy.

Goffman's observations on total institutions and our observations on nursing homes suggest that the features of an autonomous polity are absent from a nursing home patient's living situation. While the nursing home itself may have a limited amount of political autonomy, the nursing home patient does not. This suggests that one needs to go beyond the three models discussed above when deciding what autonomy means and how to provide it in a nursing home.

One might, of course, object that there is a difference between saying that the above preconditions are necessary for an autonomous individual and that they are part of the definition of autonomy. Indeed, did we not just concede that it is essential for any autonomous entity to be able to effectively deliberate? Such an objection is justified, but limited. One can define an apple by describing its color, size and shape, but by omitting that apples grow on trees and are edible, one has missed essential features of the phenomenon under consideration. The definition of autonomy does not require the above preconditions, but a definition that ignores them ignores a basic feature of autonomy.

VI. EXTENDING AUTONOMY BEYOND DECISIONMAKING

We have already seen that the free action model of autonomy is of limited help in providing ways of organizing the day-to-day life of nursing home patients to promote autonomy. While the effective deliberation model is in many ways more sophisticated, it is even less helpful for our task. The routine life of long-term nursing home patients lacks discrete, major decisions with clearly identifiable benefits and harms. Only the decisions concerning the outside world, such as discharge and subsequent placement or selling one's house, constitute problems of the sort for which one might expect autonomy as effective deliberation to be the appropriate model. For the life of most nursing home patients, the effective deliberation model is largely irrelevant. The major autonomy problem for nursing home patients is precisely the lack of things about which to effectively deliberate. There are few meaningful choices for patients in nursing homes for which it is reasonable to suggest that the staff should carefully inform the patient about the risks, benefits, nature, purposes and alternatives. It is this absence of things with substantial meaning for patients that is ethically problematic and that needs to be included in a conception of autonomy.

Equally problematic for our goal of promoting autonomy in the nursing home setting is that neither the free action model nor the effective deliberation model give any indication of identity corroding

features in nursing home organizations. If a strong independent sense of self is as essential to autonomy as the Greek city-state metaphor suggests, then our model of autonomy should not ignore features of the nursing home that are corrosive of such a sense.

VII. AUTONOMY AS CONSISTENCY

The discussed conceptions of autonomy focus on isolated, discrete acts. This analysis, while valuable, has limited applicability for our purposes. Rather than focus on discrete decisions, the analysis of autonomy in long-term care must deal with patterns of living precisely because it is about long-term care. A person's life is not merely a series of individual acts without connection. Human activity is more integrated than that. Autonomous acts are accomplished by people who have a past, a present and a future. People have goals and interests that bind their activities together in coordinated ways. Reading a book, learning to cha-cha, and getting a Ph.D. are groups of activities of varying length, complexity and importance. Individual actions take on added meaning in the context of a person's long-term goals. Someone whose actions are both free and based on effective deliberation, but who has no long-term goals, no sense of past or present commitments to call her own, seems more like a computer than an autonomous person. Knowledge of these larger goals may also shed light on the reasons for what appeared to be, given the other criteria, less than fully autonomous behavior. For example, a person may not spend time trying to understand everything about a particular decision because, in the scheme of that person's life, the decision is not critically important. Thus, although the decision seemed less autonomous, given the criteria for effective deliberation, when one evaluates the act in light of a person's long-term concerns, the behavior seems more autonomous. A 50-year-old woman, who resentfully spends much of her time caring for her aged parents rather than returning to her career, might be said to be acting non-autonomously in a free action framework. Yet she may well be acting autonomously from a consistency perspective if the original commitment to care for them was freely undertaken.

A different way to think of autonomy is to consider how actions fit together. Instead of analyzing the autonomy of an action as an isolated unit, autonomy can be analyzed in terms of people's long-term goals, current commitments and past activities.⁴⁸ As Gerald

48. LAWRENCE HAWORTH, *AUTONOMY: AN ESSAY IN PHILOSOPHICAL PSYCHOLOGY AND ETHICS* (1986); Ronald Dworkin, *Philosophical Issues in Senile Dementia* 20-32 (August 1986) (unpublished manuscript) (on file with author).

Dworkin puts it:

This view of autonomy focuses not on individual decisions one by one, but the place of each decision in a more general program or picture of the life the agent is creating and constructing, a conception of character and achievement that must be allowed its own distinctive integrity.⁴⁹

The following analogy may be helpful. Imagine trying to understand sentences or paragraphs in a novel merely by analyzing the constituent words and phrases in isolation from other sentences and paragraphs. Every sentence of the story may be well-written, clean, concise and reasonable. Yet, this limited reading alone would not tell if the story is well-written or if the characters make sense in light of the rest of the story. To analyze the novel's quality, one would have to determine if the elements of the story made sense in terms of the story line as a whole. The same is true of autonomy. To assess whether a particular action is truly an autonomous act requires examining the context in which the act occurs. We have therefore tried to develop a conception of autonomy that takes into consideration a fuller, more integrated picture of a person's life. In this sense, we are taking a novelist's view of an action. It can only be understood in terms of the individual's history, the story in which he currently sees himself involved, and the long-term direction in which he orients his life.

This approach to autonomy assesses the autonomous character of one's life rather than the autonomy of each individual act. This concept seems most relevant to our task of ameliorating the impact of a nursing home setting on the autonomy of the elderly. Life in such a setting, we have shown, is characterized not by major decisions with significant impact on individuals' lives, but by mundane activities that require little or no conscious decisionmaking.

Our alternative conception of autonomy, autonomy as consistency, emphasizes that the autonomous activity be consistent with an individual's commitments, values and life plans—that the person's activities are roughly consistent with the individual's self. It is an individual's involvement with, or acceptance of, an activity or series of activities that makes them autonomous. Autonomy as consistency places special emphasis on the coherence between the activity in question and the patterns of activity and commitment with which one has been, is, or foresees oneself involved in over the long term.

There are three basic dimensions of an act's consistency. The first concerns how the action fits in with the person's past activities—

49. See Dworkin, *supra* note 47, at 24.

roughly whether an individual is acting in character⁵⁰—and how consistent the act is with personal historical values. The second dimension deals with current values. The third concentrates on future goals and enterprises.

The initial, historical, concept of autonomy as consistency is exemplified in comments such as “it’s just like Mom to not want to go to the dance” or “Dad was always a stubborn guy.” One looks at both the activities the individual has engaged in and how they were engaged in, e.g. enthusiastically or reluctantly, and also at the person’s previously stated goals and motivations, in order to determine whether or not an activity is autonomous.

This view of consistency captures our belief that a person’s existence is more than a random collection of choices and acts. Instead, a person is an entity that develops within relatively persistent and enduring patterns. The problem with an over-reliance on this one dimension of consistency is that it suggests that a person’s self is largely static and does not change over time. In other words, a retrospective analysis of autonomy does not allow for autonomous changes in a person’s life and direction. One’s goals and commitments can change as one ages, gathers new experiences, or finds oneself in different circumstances and with different companions. However, in spite of its limitations, this retrospective concept of consistency is sometimes the only relevant dimension, as with a severely demented patient who can no longer give us reasons for what seem to be inconsistent actions. Thus, a richer conception of autonomy as consistency will take into account one’s current views and aspirations.

We have mentioned a second type of consistency, one that defines autonomous activities as consistent with current values and commitments. One way of conceptualizing this type of consistency is to focus on the individual’s identification with activities. Do I see the activity as consistent with who I am? Are these activities consistent with my values and my emotional and personal commitments? The more one identifies with an activity as one’s own, the clearer it is autonomous. As one’s identification with an activity becomes more remote, the activity is less clearly one’s own and, thus, less autonomous.

Identification makes for only a partial understanding of this type of consistency. The term “commitment” is intended to refer to the fact that, as a social actor, one is not always completely free to change one’s mind. A particular patient may wish to go out for a visit to the

50. See Miller, *supra* note 26, at 24.

mall but feel like she must stay and keep her depressed and lonely friend company. While she might be happier if she went to the mall, relationships involve commitments individuals would sometimes rather ignore. Assuming that the relationship was undertaken willingly, actions consistent with those commitments are autonomous and should be honored. Indeed, the absence of such commitments creates an isolated individual, not an autonomous one.

A final component of autonomy as consistency is consideration of the activity in light of a person's long-term goals and enterprises. These can vary from a specific goal, such as learning to play the piano, to a more encompassing goal, such as becoming a good parent. Whatever an individual's past or current commitments, human beings usually live at least partially in the future. Individuals have conceptions of desirable changes that they try to effectuate, both in their own lives and that of others about whom they care.

When speaking of autonomy as "self-direction," it is important to remember that a "direction" usually goes somewhere. One needs to appreciate the directionality of self-direction. Autonomous activity implies a goal toward which it is directed or an undertaking of which it is a part. Moreover, such a goal does not have to be focused on one's self. Many elderly individuals are deeply committed to working for their churches and their communities, to say nothing of their families. Assuming such commitments are freely made, they may be important parts of the individuals' autonomous selves.

Of course, an elderly nursing home patient, who is weak from a long confinement and whose social relations have deteriorated as her peers have died and her children moved away, may have a limited horizon. Unlike a younger person, who has at least some plans for the years ahead, the patient may only plan for the next few weeks. However, that does not limit the importance of the consistency of her action with her limited long-term goals.

Whether or not a particular act is autonomous can depend on one's feeling about an undertaking and its effect on one's self. One's commitment to an enterprise may change, thereby changing one's assessment of an activity. For example, Ms. Jones may autonomously undertake to learn to play the piano. However, as she begins to learn how to play, she realizes that while she likes the attention she gets from the other residents of the nursing home, she does not like to play the piano. Playing the piano takes a great deal of time. She realizes that learning to play the piano means that she will have to give up other activities she really enjoys. Soon she wishes that she had never played the piano. However, she continues to play because the staff,

believing that playing expresses an interest in life and a commitment to the future, repeatedly encourages her to continue even when she is reluctant. While she may have contemporaneous commitments to play at a concert that afternoon everyone has been planning for, she clearly cannot be held to a recital two months away. This example shows the complex relationship between an undertaking, self-identity and autonomy. Mrs. Jones' loss of commitment to learning to play the piano changes an autonomous activity into a largely non-autonomous one.

Consistency is not the sole definition of autonomy.⁵¹ Just as effective deliberation does not deal with the relationship of an act to the individual's broader life circumstances, so does the consistency criteria not provide a very good basis for understanding the autonomy features of the act itself. Unlike the free action criterion, consistency says relatively little about the moral acceptability of pressures that come to bear on an individual's goals or behavior. Thus, any complete theory of autonomy for the elderly must deal with questions of free action, effective deliberation, and consistency.

For our purposes—describing the impact of institutional structures on autonomy—"consistency" provides a particularly useful framework. It suggests that past legal reforms designed to promote autonomy will not have a significant effect on the real lives of elderly persons living in nursing homes. The question thus becomes what kinds of legal reforms would have an effect?

This is a difficult subject, one for which we neither have the expertise nor the space to discuss adequately. We are pessimistic that legislation regarding the living conditions of elderly nursing home residents can ever solve the problem. The law is a blunt instrument when it comes to modifying interpersonal relationships. It sets minimal standards for human behavior and is not well-suited for encouraging nursing homes to pay more attention to their occupants' actual goals and commitments. Given these attributes, we are uneasy about urging new legislation. The history of legislation in this field has been to pass laws which, while consuming a large percentage of the staff's time and energy, do very little to promote autonomy.⁵²

Legislation is better suited to ensuring that nursing homes meet certain minimal safety criteria. While this is important, we think it is equally important that safety not be viewed as the only significant value in nursing homes. One should bear in mind that legislation

51. Daniel Callahan, *Autonomy: A Moral Good, Not a Moral Obsession*, 14 HASTINGS CENTER REP. 40-42 (1984); Collopy, *supra* note 17; see Dworkin, *supra* note 47.

52. ROSALIE KANE & ARTHUR CAPLAN, *EVERYDAY ETHICS* 296-309 (1990).

designed to promote safety may serve to decrease autonomy. Elderly persons may be willing to take some risks to lead what they consider a fuller life.

Similarly, legislation requiring higher standards for employees of nursing homes should be examined quite critically. One must remember that nursing homes are, for most occupants, homes, not long-term hospitals. From our experience, health care personnel's preoccupation with "body care" limited their attention to patient autonomy.⁵³ Instead of concentrating on qualifications, legislation would be more profitably directed at raising nursing home employees' benefits, thus encouraging persons to enter and remain in the field.

VIII. CONCLUSION

We have tried to show that if one is to promote autonomy, either through law or less formal means, it is important to appreciate the complexity and mutual embeddedness of human activities. At least in the nursing home context, treating autonomy as the property of isolated acts seems unhelpful in dealing with the profoundly anti-autonomous features of total institutions. One needs a more complex model of autonomy precisely because these features have nothing to do with a lack of information and are only modestly related to the presence of coercive pressures.

We have tried to show that a truly autonomous human being is a complex person with a history, a set of values, commitments, and an image of an intended future. If promotion of autonomy is a serious legal and ethical goal, one must recognize that it cannot be achieved by a simple formulaic analysis of discrete acts made by allegedly "rational" people, whose life involvements do not extend beyond their privately held and entirely personal preferences. Our model of autonomy as consistency is intended as a modest step in that direction.

53. JABER F. GUBRIUM, *LIVING AND DYING AT MURRAY MANOR* 123-57 (1975).