

Dependence and Autonomy in Old Age

An Ethical Framework for Long-Term Care

Second and Revised Edition

George J. Agich



CAMBRIDGE
UNIVERSITY PRESS

PUBLISHED BY THE PRESS SYNDICATE OF THE UNIVERSITY OF CAMBRIDGE
The Pitt Building, Trumpington Street, Cambridge, United Kingdom

CAMBRIDGE UNIVERSITY PRESS

The Edinburgh Building, Cambridge CB2 2RU, UK
40 West 20th Street, New York, NY 10011-4211, USA
477 Williamstown Road, Port Melbourne, VIC 3207, Australia
Ruiz de Alarcón 13, 28014 Madrid, Spain
Dock House, The Waterfront, Cape Town 8001, South Africa

<http://www.cambridge.org>

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First published 2003

Printed in the United Kingdom at the University Press, Cambridge

Typefaces Minion 10/12 pt. and Dax *System* \TeX 2 ϵ [TB]

A catalog record for this book is available from the British Library

Library of Congress Cataloging-in-Publication data

Agich, George J., 1947 –

Dependence and autonomy in old age : an ethical framework for long-term care /

George J. Agich. – 2nd edn., rev.

p. cm.

Previously published as: *Autonomy and long-term care*.

Includes bibliographical references and index.

ISBN 0 521 00920 0 (paperback)

1. Aged – Long-term care – Moral and ethical aspects. 2. Autonomy (Psychology) in old age.

3. Autonomy (Philosophy) I. Agich, George J., 1947 – *Autonomy and long-term care*. II. Title.

RC954.3 .A44 2003

174'.2–dc21 2002031406

ISBN 0 521 00920 0 paperback

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Introduction

Autonomy and long-term care are a remarkably paradoxical conjunction. Individuals need long-term care because they suffer illnesses and incapacities that compromise their ability to function independently or to choose rationally. Yet the standard concept of autonomy in bioethics stresses the ideals of independence and rational free choice, ideals that appear ephemeral in the face of the wide range of impairments that cause individuals to need long-term care. No doubt such individuals are vulnerable and so might benefit from the protection afforded by various autonomy-derived rights such as noninterference. The paradox is that the underlying concept of autonomy involves a view of persons as robust and independent, whereas the reality of long-term care shows individuals who need support and companionship, needs that seem inimical to this ideal. The paradox thus involves the contrast between capacities central to standard views of autonomy and the actual capacities of individuals who need long-term care: independence versus dependence and capacities associated with agency versus functional frailties. The paradox arises when the fragility and vulnerability of individuals needing long-term care are approached from the perspective of the standard view of autonomy that implicitly involves a robust concept of individual capacity.

The standard view of autonomy is a product of the deep and variegated liberal tradition of thought that is at the foundation of contemporary democracy and bioethical thought. In this view, autonomy is primarily a phenomenon involving independence of action, speech, and thought. It provides the broad foundation for a wide range of political, legal, civil, and human rights and the philosophical basis on which individuals can resist the coercive interference of external authorities or powers in their lives.

The ideals implicit in this concept of autonomy include independence and self-determination, the ability to make rational and free decisions, and an ability to accurately assess what constitutes the individual's own best interest. This concept of autonomy has led to worries about paternalism, the use of (varying degrees of) coercion to impose another's vision – where the other might be the state, private institutions, or individuals – on a single individual or class of individuals. The concept of autonomy so understood supports a set of values such as independence and self-determination that have provided

the normative standards around which tyranny, oppression, and even the benevolent use of power over vulnerable individuals have been opposed.

If we approach the task of enhancing the autonomy of elders in long-term care from a critical appreciation of this tradition, an occlusion becomes obvious that requires attention. Autonomy and long-term care are each rather diffuse cultural ideas. This is so much the case that it is difficult to pierce through the cultural and ideological aura that surrounds these terms. To realistically reassess the meaning and function of autonomy in long-term care, then, requires that we pay attention to the symbolic meanings of autonomy and long-term care, because these meanings not only set the context or stage for the analysis, but also complicate its execution.

Long-term care images

The term *long-term care* conjures up many images; few of them are felicitous. Long-term care seems to hang like a pall covering the inevitable coffin that awaits us all. Surprisingly, in our culture it is less death than long-term care that strikes us as so repugnant. This reaction may represent a profound psychological defense against death, to be sure, but its immediate effect is to place long-term care center stage in an unfavorable light. The images of long-term care are images of frailty and despair, loneliness and destitution, and above all a profound sense of loss, a loss not only of things, but of who and what we are. These attitudes undoubtedly reflect society's perceptions of the institutions that are often thought to be the main providers of long-term care, namely, nursing homes. Anthropologists and sociologists regard nursing homes as anything but humane (Gubrium 1975; Henry 1963; Kayser-Jones 1981; Laird 1979; Lidz, Fischer, and Arnold 1990; O'Brien 1989; Savishinsky 1991; Shield 1988; Vesperi 1983, Watson and Maxwell 1977). They are frequently seen as places of exploitation (of staff as well as of residents). They stimulate either moral outrage or revulsion. These reactions are shaped by latent image: a blabbering, incoherent, disheveled elder strapped into a geri-chair, withdrawn or beckoning for attention, but invariably ignored by staff who, without emotion, expression, or enthusiasm, perfunctorily perform the onerous tasks of daily bed and body work that are made even more difficult by the niggling demands of residents. The image is coupled with the olfactory assault of urine, excrement, and myriad other unpleasant odors that suffuse drab corridors or insipid sitting rooms where residents sit transfixed, each in his or her own world. There are also disturbing sounds of people moaning from down the hall, crying out, one elder scolding another harshly, others weeping in protest. No wonder that the pall of long-term care is as feared as the coffin it covers! Long-term care seems suffused with a terrifying absence, the absence

of a meaningful sense of control, dignity, or identity. It is an appalling state of living death, somewhere just this side of madness.

Like many taken-for-granted beliefs, the nursing home-dominated image of long-term care is in its general form brutally apt, but it harbors latent meanings that require careful exegesis and qualification. For one thing, not all long-term care is institutional. Despite perceptions to the contrary, only 4.3 percent of those over the age of 65 live in institutions, a percentage that rises dramatically with age, ranging from 1.1 percent for those aged 65–74 years to 4.5 percent for those aged 75–84 years and 19 percent for those aged 85 and above (Administration on Aging 2000). Twenty-five percent of those in institutions will spend at least 12 months there, and at least 10 percent will be patients for 5 years or more (Kemper and Murtaugh 1991: 597). The chance of being in a geriatric facility significantly increases with age.

The confluence of several macro trends in developed countries – older population age structures, higher incidence of noncommunicable disease, lowered fertility, increased geographical mobility, and the rapid advance in medical technology – has led to a steep rise in numbers of institutionalized elderly. (Kinsella and Velkoff 2001: 69).

Cross-national comparisons of living arrangements of elders lead to three conclusions: women in developed countries are more likely than men to live alone as they age; generally both elderly men and women in developing countries live with adult children; and the use of institutions to care for frail elders varies widely around the world (Kinsella and Velkoff 2001: 65). In the United States, approximately 22 percent of the elderly population will spend some time in an institution after they reach the age of 85 (Siegel and Taeuber 1986: 101), but ‘the fact remains that relatively small proportions of elderly populations reside in institutions at any given time’ (Kinsella and Velkoff 2001: 69). Most elders do not live in nursing homes, but remain in contact with their families and friends (Shanas 1979). In 1998, 67 percent of older non-institutionalized persons in the United States lived in a family setting (Administration on Aging 2000). Even for institutionalized elders, dozens of individuals outside the institution, including family, friends, neighbors, clergy, social workers, lawyers, and doctors, will be involved in their care and directly touched by their fate (Savishinsky 1991: 9–10).

Family, friends, or in-home services thus deliver a considerable amount of care in the home. Such care involves help with the tasks of daily living ranging from personal assistance and services such as food preparation, hygiene, administration of medication, to companionship, assistance in shopping, and entertainment. Indeed, discussions of long-term care frequently presume that the nursing home is the natural locus of long-term care, whereas it is actually a member of a heterogeneous class of services. Although the nursing home paradigm distorts our understanding of the reality and issues associated with

long-term care, its prominence indicates something quite significant about our latent cultural expectations and anxieties.

In reality there are, at least, two kinds of nursing homes (sometimes existing within the same physical structure): the so-called skilled nursing home and the institution that provides only intermediate care (Lidz, Fischer, and Arnold 1990). The distinction in kind makes an important practical difference. In the United States, Medicare pays only for skilled nursing care, as does most private insurance. Medicare-paid nursing care is designed to aid the transition from hospital for elders who have suffered an acute health crisis. It is short term and rehabilitation oriented. There are strict time, disease, and dollar limits (Diamond 1986: 1288). Although Medicare is the only real national long-term care program in existence in the United States, it is remarkably short-term oriented. Medicaid pays for nursing home care only after a patient has become indigent. As a social safety net, it is situated frightfully near the ground. No wonder elders (and their families) perceive its support with such apprehension, for it means a fall, sometimes a precipitously long fall, from economic sufficiency to indigence. This economic fact adds to the perception of long-term care as involving a loss of independence. This situation is not confined to the United States. Reiner Leidel (1995: 50) reports that old-age dependency has been rising during the last 20 years in almost all 12 states of the European Union. Elders who are declining in health and ability to care for themselves understandably live in apprehension of the economic (as well as psychological and social) consequences of their fall. This point is driven home by the data on disability in old age:

In 1994–95 more than half of the older population (52.5%) reported having at least one disability. One-third has at least one severe disability. Over 4.4 million (14%) had difficulty in carrying out activities of daily living (ADLs) and 6.5 million (21%) reported difficulties with instrumental activities of daily living (IADLs). The percentages with disabilities increase sharply with age (Administration on Aging 2000: 11).

At the same time, Kinsella and Velkoff report that: ‘Recent data and rigorous analysis strongly suggest that rates of disability in a number of developed countries are declining’ (2001: 41). When disability strikes, the cost of medical care can drive elders toward becomingly paupers (Diamond 1986: 1289). Destitution is the norm for those individuals who are cut off from the discretionary income that in Western societies is the almost universal measure of social status and worth. This point applies equally to those who have recently fallen from economic grace, as well as to those who have always depended on public aid, because discretion over the use of even limited funds is as important for the poor as for the middle class or wealthy.

The everyday reality of the nursing home is thus strikingly dissonant with the competing popular image of retirement as a stable life filled with fulfilling leisure activities. Long-term care represents a state of economical, psychological,

and social instability. It is little wonder that long-term care encourages rhetorical appeals to autonomy. Autonomy in long-term care is a slogan employed for the liberation of the frail and destitute old. Increasing autonomy in long-term care is bioethics response to the complex cultural crisis that disability and aging represent. Like many slogans, it needs careful analysis if it is to promote any practically effective and ethically defensible reforms. Understanding the cultural meaning of the nursing home as the symbolic setting for long-term care can help us to understand both the attraction and limitation of the appeal to autonomy as a central ethical concern and principle for long-term care.

Given our cultural revulsion to the sometimes brutal and stark reality of nursing home life, appealing to considerations of autonomy both salves our sense of moral outrage and yet preserves the distance that we so dearly want to maintain between ourselves and the idea of loss and incapacity that figuratively oozes from the image. Autonomy is attractive because it provides a ready-made vernacular of rights that seem to capture what at first glance bothers us about long-term care, namely, the effacement of autonomy and functional capacity, expressed in the pronounced dependence of nursing home existence.

Nursing homes are examples of what Erving Goffman termed total institutions (Goffman 1960, 1961). Like army barracks, mental hospitals, nunneries, and prisons, nursing homes are *total* in the sense that they isolate, control, and reconstitute the daily lives of their residents. Stripping away and reconstituting the identities of their residents through rituals of initiation and degradation accomplish this. They require the participation of the residents in certain kinds of prerequisite activities and behaviors for gaining privileges that we often take for granted as everyday liberties. Opposition to total institutions is a well-known theme in democratic social thought. Ironically, the consequence of the most committed criticism of such institutions is not always ideal as the case of the deinstitutionalization of the mentally ill shows. Panaceas, appealing as they seem in theory and as powerfully as they perform in rhetoric, seldom work in practice. In the case of severely debilitated elders, it is paradoxical to acknowledge the need for institutional care and to regard the oppressive locus of such care as reformable by a large injection of liberal values.

The pivot of talk of liberalizing nursing home care is the concept of autonomy. It is manifested in numerous well-intentioned proposals, such as insisting on full-disclosure preadmission agreements, creation of patient ombudsmen or nursing home ethics committees, insisting on delineation of a basic set of resident rights, or establishment of detailed values histories for each resident (Hofland 1990). Collectively, these approaches attend to what bothers us most about the surface reality of nursing home existence, yet saves us from having to deal with the messy deep reality of being old and frail. It saves us from confronting the economic, physical, psychological, and social conditions that engender nursing home care and the more difficult ethical questions that the daily care of individuals requiring long-term care poses.

Autonomy

Like long-term care, autonomy involves a diffuse set of meanings that are culturally as well as philosophically determined. It would thus be a mistake to assume that the term *autonomy* has a consistent meaning or usage in ethical theory, political theory, or everyday contexts. Recent philosophical work on autonomy has included a discussion of a range of concerns that generally tends to avoid use of the term itself (Christman 1988, 1989). Autonomy refers to a broad set of qualities that are generally, though not universally, regarded with approval. Autonomy is taken to be equivalent to liberty, either positive or negative liberty in Isaiah Berlin's sense (1969: 118–72), self-rule, self-determination, freedom of will, dignity, integrity, individuality, independence, responsibility, and self-knowledge; it is also identified with the qualities of self-assertion, critical reflection, freedom from obligation, absence of external causation, and knowledge of one's own interest, and is related to actions, beliefs, reasons for acting, rules, the will of others, thoughts, as well as principles (Beauchamp and Childress 1983; Dworkin 1978, 1988; Gilbert 2000). Treatment of autonomy in the gerontological bioethics literature has a similar wide range of meanings (Thomasma 1984) involving a diverse set of tensions or polarities (Collopy 1986, 1988) that suggests that respecting autonomy is likely to be far more complex than is apparent at first glance (Donchin 2000).

This wide range of usage suggests that it is unlikely that an essential or core meaning underlies these various employments; therefore, it would be futile to try to develop an essential definition of autonomy as a starting point for practical ethical analysis of long-term care. Rather than arguing for a core or essential definition of autonomy, it would be best to acknowledge that the meaning of autonomy is irremediably context dependent. It would be wrong to conclude that these observations imply that the meaning of the concept is so relative that meaningful philosophical treatment is precluded. Certainly, some accounts of autonomy will fail because they try to force the concept to accomplish what it is incapable of achieving in certain contexts of concern. An adequate philosophical treatment of autonomy in long-term care must come to terms with the contextual nature of the concept of autonomy instead of relying on abstract, theoretically provided definitions. This point implies that the concept of autonomy in long-term care must be shaped with a clear vision of the practical purposes that autonomy might serve in the context of long-term care itself.

Autonomy, however, is not only an important philosophical concept; it is a significant cultural ideal. In the guise of independence, it has been a perennial feature of American society. In the early days of the Republic, Alexis de Tocqueville noted the peculiar tendency of Americans to draw apart and to keep to themselves: 'Each citizen is disposed to isolate himself from the mass of his fellows and to draw apart with his family and friends. It not only makes each man forget his forefathers, but it conceals him from his descendants and

separates him from his contemporaries' (quoted in Christiansen 1983: 35). More recently, American society has been characterized as the *lonely crowd* (Riesman 1950) and as engaged in a collective pursuit of loneliness (Slater 1970). Indeed, some authors have noted that the concept of individual freedom held by elderly Americans and their families rests on a sweeping faith and confidence of the individual in his own competence and mastery, which, in turn, produces a definition of personal identity predicated on independence and self-reliance (Clark 1971: 265). This cultural ideal results in a variety of secondary defenses against dependence: a denial of need, hostility toward helpers even in the face of disabilities and limitations that require assistance from others, contempt for the real or imagined weakness of others, and, in some cases, an inflated self-image. The cultural attitude that constitutes an aversion for dependence has been termed *counterdependence* (Christiansen 1983: 52–128; Rogers 1974).

The attitude of counterdependence assumes that any form of dependence is tantamount to a degrading submission. This view is understandable given the dominance of the concept of autonomy as negative freedom, namely, the idea that individual freedom consists fundamentally in the noninterference of others in the life of the individual. The over-determination of negative freedom is partly due to its association in Anglo-American political and ethical theory with a set of beliefs about individual freedom that prominently includes self-reliance, personal preference, and self-assertion. (Christiansen 1983: 41–4)

Self-reliance refers to the capacity to provide for one's own needs. In the course of aging, however, dependence begins as the diminishment of one's powers of self-reliance. The problem is not with self-reliance as such, but rather that self-reliance defines individual worth. Lacking the ability to be self-reliant contributes to the feeling of worthlessness experienced by many old people. If identity and value are grounded in one's ability to be self-supporting, then physical infirmity and disability can compromise one's sense of personal worth precisely by compromising self-reliance. This point is admirably summarized in the notion of active life expectancy as an empirical measure of population health. This measure involves activities and abilities such as bathing, dressing, transfer or mobility, and eating that are correlated with a sense of functional well-being; loss of these functional abilities represents loss of independence (Katz et al. 1983).

A second concept associated with the idea of individual freedom is personal preference. Personal preference focuses discussion of autonomy on the phenomena of choice and decision. Indeed, choice is of such importance that attention to one's wishes, desires, and impulses comprises a significant set of concerns in the ethical analysis of human action. This focus, however, makes it difficult, if not impossible, to question whether the values implied by one's desires, impulses, or wishes are worth having. From the fact that I choose something on the basis of my desire, for example a certain kind of food, it

does not follow that that something is good for me. Attention to my wants or preferences, however, not only renders the question of the good of the objects of choice irrelevant, it restricts the domain of ethics to but one feature among many defining human moral agency. Choice is undeniably important, but not all-important. Attention to the phenomena of choice and decision making has had the unfortunate consequence of rendering otiose other features of autonomy.

Third, the concept of individual freedom includes the value of self-assertion as a basic requirement, namely, that one actively pursues the fulfillment of one's desires. It is not enough to have desires or to make choices; one must be actively engaged in their fulfillment or accomplishment. So construed, autonomy commits individuals to a seemingly ceaseless pursuit of the fulfillment of their preferences, for without such fulfillment autonomy itself is seen as useless or empty. Whatever thwarts the attainment of one's desires is seen as curtailing freedom; hence, noninterference becomes the obvious imperative under this concept of autonomy. It is commonly admitted, however, that this view is odd and even destructive when applied to children, yet the restraint or mastery of desire that is characteristic of maturation seems to be regarded somehow as inappropriate or wrong in the case of adults! A moment's reflection should indicate that this is a fundamental mistake. Acquiring any sort of skill or expertise, whether as a child or adult, involves discipline of unruly tendencies or desires. Learning always involves a subordination of the immediate fulfillment of desire to wider ends and purposes.

Autonomy and long-term care: the problem

The dissonance between the image of the robust, striving, and unencumbered individual making her own way competently in the world and even the most banal limitations that underlie the need for long-term care should be readily apparent. Some adult individuals, for example frail elders, are generally not fully self-reliant; they often lack the psychological ability, physical energy, or social and economic prerequisites necessary to pursue their preferences. The view of autonomy that takes as a defining feature the pursuit of all preferences – just because those preferences are preferences of the individual – seems to foredoom as paternalistic and objectionable any attempt to respond to an elder's evident need. Where desire reigns, need recedes. Thus, the diminished capacity that brings elders into long-term care contributes to the view that dependence entails subservience and inferiority; but if independence is only, or primarily, valued, then we should not be surprised to find that responding even to basic human needs is fraught with contradiction.

Addressing the conjunction of autonomy and long-term care thus presents two types of problems at two different levels: first, the level of concepts

involving the meaning of long-term care and the meaning of autonomy and, second, the practical difficulties associated with actual autonomy and the reality of long-term care. These four elements interplay in a complex pattern.

The most striking feature of long-term care is that adult individuals suffering from diseases and illnesses of being old experience a compromised vigor and ability to function that requires regular care ranging from help in the activities of daily living, such as housework, food preparation, and hygiene, to highly skilled nursing and medical care. Functional disabilities that frequently bring with them vulnerabilities define elders as a class of individuals requiring long-term care. Because elders requiring long-term care often deviate in obvious ways from the ideal of the competent, rational, and free decision maker that is implicit in the commonplace understanding of autonomy, various mechanisms have been devised to protect elders from unwarranted intrusion. These mechanisms include the use of various legal advocacy and guardianship measures to endow elders with specific rights as well as the use of surrogate decision-making procedures, especially in the case of refusal of life-sustaining medical care. Reliance on surrogate decision making is an interesting development in long-term care, primarily growing out of the acute care context (Buchanan and Brock 1989). The reality of long-term care apparently forces even the staunchest proponent of autonomy as independence to deal with the reality of an impaired decision-making capacity or incompetence that is an ineliminable feature of long-term care.

This response is both understandable and troubling. It is understandable because the reality is such that elderly individuals who require long-term care frequently experience various physical, psychological, and social disabilities and deprivations that should give us pause. These frailties suggest that the ideal of the person that underlies the standard view of autonomy is inapplicable in many of these cases or simply fails to provide much practical assistance for either restoring or sustaining the degree and kind of autonomy that is present. Primarily because it is dominated by an abstract and ideal concept of the autonomous individual that fails to jibe with the reality of long-term care, the concept of autonomy as independence simply proves inadequate and has to be refurbished if it is to function importantly in the context of long-term care.

These observations point to the second problem that arises if we critically reflect on the applicability and usefulness of commonplace understandings of autonomy in long-term care, namely, the nature of autonomy itself. The traditional liberal view of autonomy tends to direct attention to specific problems associated with decision making. This view is not surprising given the powerful place that the related concepts of independence, self-determination, and rights enjoy in our culture. These concepts, embodied in the Anglo-American legal system, exert a significant influence on bioethical thinking. Hence, autonomy has come to be defined primarily in terms of a concept of human persons as rational, independent agents and decision makers, who are assumed to be

competent and who can be understood without serious reference to society or history.

Independent decision makers are insulated by a fabric of rights that protects them from the intrusive and coercive influence of the state or other individuals. Indeed, the individual is often seen as standing in opposition to society or the state that is assumed to pose a threat to the integrity of the self. Individuals are idealized in such a way that the expression of uniquely individual beliefs and values is given primacy over other goods or values. Furthermore, decision making is regarded as a rational process that can be understood or explained in terms of decision theory; communicative interactions between individuals are thought to involve primarily the exchange of information as evidenced by the stress on disclosure of information in the legal doctrine of informed consent. This view of autonomy is remarkably abstract and assumes an ideal view of persons. It is not only deficient as a general theory of the meaning of actual autonomy, but, more pointedly, is not well suited for conceptualizing the ethical problems associated with long-term care. For this reason, the concept of autonomy itself must be reassessed and revamped if it is to play a significant role in theoretically and practically clarifying the ethics of long-term care.

The assumptions and implications of the commonplace understanding of autonomy as independence orient reflection on long-term care to relatively dramatic conflicts expressible in terms of rights. As a consequence, more mundane day-to-day experiences and encounters of elders with caregivers in long-term care tend to be overlooked, in part because they lack the conflictual, dramatic, and discrete characteristics required by the standard view. A truly helpful ethics of long-term care, however, would incorporate a concept of autonomy that is interstitial to the typical everyday reality of long-term care, not one that fixates on the unusual or atypical. The context from which the main concept of autonomy comes is the political/legal realm; it is further supported by the reality of acute care medicine that hand-in-glove seems to support a concept of ethics that is problem or issue based. Unfortunately, political/legal treatments of autonomy typically marginalize questions of relationship, quality of care, and the affective dimension of clinical encounters, concerns that are significant in long-term care as well.

The common view that autonomy is tantamount to independence has important implications for long-term care. First, the cultural dominance of this model of autonomy creates a backlash against dependence of any sort, so that the frail and infirm old who require long-term care are especially vulnerable to the pejorative meanings associated with dependence. They are seen and frequently see themselves as burdensome and less than full persons. As a class, these elders are treated as deviants from the images of robustly active retirement for which the oxymoron *active retirement* has become a battle cry.

Second, autonomy as independence injects a predominantly adversarial and conflictual set of metaphors into thinking about long-term care. Like so much

discourse in our society, the language of rights eclipses other ethical language. As a result, long-term care is mainly thought of in terms of problems that can or should be dealt with by establishing legal rights or promulgating regulations. The goal of these efforts is to force caregivers to conform to the standards of a liberal polity and respect the rights of their wards. Ironically, when elders lose the abilities assumed to be present for autonomy as independence, society is less enthusiastically committed to dealing with the aftermath. Frail and sick elders are infantilized by social institutions and programs that afford them entitlements to *services*, but under conditions that hide them from public view.

Third, the asymmetry between autonomy as negative freedom (the vision of the agent as independent and rationally competent) and the economic, physical, psychological, and social needs of elders propelled into long-term care forces to prominence the question 'Is autonomy really the central value and concept for thinking about the ethics of long-term care?' It is if it can be phenomenologically re-interpreted to sustain an ethically robust framework for the practice of long-term care.

The goal of this work is to articulate just such a framework. Without rejecting the central commitments of the liberal view of autonomy, I propose a complementary framework to open the everyday reality of long-term care to ethical analysis. This alternative framework develops a view of the nature of *actual* autonomy predicated on a concrete understanding of the everyday experience of autonomy in long-term care. This framework involves a shift of attention from autonomy as independence to the concrete manifestations of autonomy in the everyday world of life. The framework involves a developmentally oriented and phenomenologically derived account of the ordinary or everyday sense of autonomy in terms of concrete human action in the shared world of social life. The framework brings into focus the full range of caregiving interactions as well as the structure of caregiving relationships. It opens up the complex reality of the long-term care of elders for clinical ethical reflection.

