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0521009200 - Dependence and Autonomy in Old Age: An Ethical Framework for Long-Term Care,
Second and Revised Edition

George J. Agich

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Dependence and Autonomy in Old Age

Respecting the autonomy of disabled people is an important ethical issue for providers of long-term care. In this influential book, George Agich abandons comfortable abstractions to reveal the concrete threats to personal autonomy in this setting, where ethical conflict, dilemma, and tragedy are inescapable. He argues that liberal accounts of autonomy and individual rights are insufficient, and offers an account of autonomy that matches the realities of long-term care. The book therefore offers a framework for caregivers to develop an ethic of long-term care within the complex environment in which many dependent and aged people find themselves.

Previously published as *Autonomy and Long-term Care*, this revised edition, in paperback for the first time, takes account of recent work and develops the author's views of what autonomy means in the real world. The author writes with passion and concern about his topic, combining a scholarly, phenomenological approach to ethics and personal identity with an awareness of the needs of vulnerable older people and their carers. The book will have wide appeal among bioethicists and health care professionals.

George J. Agich is the F.J. O'Neill Chair in Clinical Bioethics and Chairman of the Department of Bioethics at the Cleveland Clinic Foundation, Professor of Clinical Medicine at Ohio State University, and Adjunct Professor of Philosophy at Bowling Green State University. His previous books are *Responsibility in Health Care* (1982), and *The Price of Health* (1986), and he is a member of the editorial board of *The American Journal of Bioethics* and other journals.

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Contents

	<i>Preface</i>	vii
1	Introduction	1
	Long-term care images	2
	Autonomy	6
	Autonomy and long-term care: the problem	8
2	The liberal theory of autonomy	13
	Pluralism, toleration, and neutrality	14
	The state and positive autonomy	21
	Some problems with positive autonomy	22
	Liberal principles in long-term care	24
	The perils of liberal theory	29
	Communitarianism and the contextualist alternative	31
	Practical implications of the debate over the foundation of ethics	35
	Conflict and conversation	37
	The function of rights	39
	Limitations of rights	41
	Paternalism and the development of persons	43
	From paternalism to parentalism	47
	Summary	50
3	Long-term care: myth and reality	51
	Myths of old age	52
	Nursing homes	56
	Therapeutic relationships	65
	Concepts of illness and disease	69
	Models of care	71
	The concept of a practice	74
	Home care	77
	Summary	81

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Frontmatter

[More information](#)**vi Contents**

4	Actual autonomy	83
	Result-oriented theories	84
	Action-oriented theories	85
	The concrete view of persons	89
	Autonomy: a developmental perspective	93
	Narrative approaches	98
	Dependence in human development	101
	Sickness as dependence	104
	Autonomy and identification	108
	The paradox of development and problems of identification	112
	Implications for long-term care	117
	Summary	123
5	A phenomenological view of actual autonomy	125
	Sociality and the world of everyday life	125
	General features of the social nature of persons	129
	Space	136
	Time	143
	Communication	152
	Affectivity	159
	Summary	163
6	Autonomy and long-term care: another look	165
	Social reality of Eastside	165
	Appeal to autonomy as independence	167
	A phenomenologically informed analysis	168
	Theories of autonomy	174
	Final thoughts	177
	<i>References</i>	181
	<i>Further reading</i>	198
	<i>Index</i>	203

Preface

After receiving numerous queries about a paperback edition for classroom and other use, I undertook revisions to *Autonomy and Long-Term Care*, the predecessor of this edition, with the intention of bringing my ideas about autonomy in old age to a larger audience. Oxford University Press, publisher of the original book, ultimately decided against a second edition. Fortunately, an arrangement with Cambridge University Press was worked out that permitted the publication of this revised edition. Dr Richard Barling, Medical Publishing Director of Cambridge University Press, has been incredibly supportive of this project as discussions with OUP proceeded. Jeffrey House and Edith Barry of OUP were also very helpful throughout these discussions and I am very grateful for their longstanding good will.

Work on this edition was supported with research help provided through the F.J. O'Neill Chair in Clinical Bioethics. The longstanding support of Nancy O'Neill, Hugh O'Neill, and the F.J. O'Neill Charitable Foundation for Bioethics at the Cleveland Clinic Foundation has been truly remarkable. Their continued support during my tenure in the O'Neill Chair has been outstanding and gratefully appreciated.

The first edition of this book was dedicated to my mother-in-law and father-in-law. My father-in-law had been diagnosed with Alzheimer's disease and required institutional care, so their view of the problems discussed therein was far more significantly 'inside' than my own. Several years ago, my own mother also developed memory loss and confusion that eventually necessitated her moving into an assisted-living center, where she resided until her death. These events are deeply personal reminders that the challenges of respecting the autonomy of disabled elders are often bound up with family relationships, commitments, and emotional meanings that must be accommodated in ethical analysis. Attention to autonomy in long-term care is thus important less for philosophical reasons than for the existential impact that disabilities create for persons who deserve our love and respect. I hope that this work challenges and helps caregivers to reexamine their commitments and practices to enhance the dimming autonomy of old people and the threatened autonomy of disabled individuals.

The primary examples used in this revision, as in the original work, are frail and disabled elders. The problems associated with long-term care apply

viii Preface

to a much wider range of chronic conditions, not all of them debilitating or end-of-life. I have dealt with some of these areas in papers written after the first edition was published: for example, the meaning of actual autonomy and long-term care in the context of chronic disease (Agich 1995a, 1995b), schizophrenia (Agich 1997), consent in research on Alzheimer's disease (Agich 1996), and the meaning of autonomy in Alzheimer's disease and dementia (Agich 1994, 1999). Others have adapted the concept of actual autonomy in empirical studies of rehabilitation (Proot et al. 1998, 2000a, 2000b, 2000c). To avoid compromising the line of argument, however, I chose not to introduce these kinds of examples in any significant way, for fear of losing focus. This omission is justified primarily because the application of the concept of actual autonomy in contexts like rehabilitation tends to confirm, rather than challenge or compromise, the main lines of my analysis of autonomy in old age.

My work on the problem of autonomy and long-term care began in 1987 when I first addressed some of the difficulties associated with its meaning and function. I saw the need for an alternative to the mainstream, liberal view of autonomy as applied to the complex clinical problems and settings of old age. A viable alternative should preserve the core commitments of liberal theory, so I avoided seeking refuge from the problems of respecting autonomy in communitarian or care ethics, even though the approaches are compatible with my own. Instead, I wanted to develop a more nuanced concept of autonomy that was more appropriate to the concrete reality of the long-term care context.

I have had little interest in cataloging the range of ethical problems in nursing homes and to some extent I have avoided directly confronting a number of important societal problems involving the aging of the population, such as the allocation of resources or intergenerational issues of justice. This work, instead, is an extended essay on the practical meaning and function of autonomy under the conditions of disability that create the need for chronic care. Its guiding idea is that autonomy is a central ethical concept in this context, but only if it can be refurbished. The argument is developed along two lines: first, an extended appraisal of the liberal view of autonomy and its applicability in long-term care and, second, a phenomenological exposition of the meaning of actual autonomy in the everyday world and in long-term care. The goal of the phenomenological account of actual autonomy is to set out a framework within which practical work on autonomy and long-term care can proceed. The analysis and discussion are at certain points rather coarse grained, because the objective of this book is programmatic, namely, to set out a framework for practical thinking about autonomy in the context of long-term care. This book does not purport to address fully the range of ethical issues associated with geriatrics and gerontology. The ethical theory in the book is not fully developed or justified to any serious extent and there is little in the way of prescriptions or normative rules to guide conduct. Instead, I have aimed to

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Frontmatter

[More information](#)

develop a framework for rethinking and reconsidering the everyday ethics of long-term care. I accept that ethical conflict, dilemma, and tragedy are inescapable features of this setting, and I do not think that theoretical analysis is the right tool to achieve the practical objectives of improving the quality of care. I strongly believe that well-motivated caregivers can improve their practices if they could be provided with a useful way to think about respecting the autonomy of persons needing long-term care. For such a framework to have practical significance, readers will need to adopt its vantage point to inform their thinking and action. The book is thus motivated by the belief that prescriptive advice is far less useful than a fresh presentation of the complex reality of autonomy to reveal its manifestations in the sometimes cold and comfortless confines of long-term care. I have the confidence that those who are situated closer to the phenomena of old age and disability are better able to devise solutions to problems or to make improvements in programs than someone trained in bioethics and philosophy.

The analysis of actual autonomy, social action, and the world of everyday life that occupies Chapters 4 and 5 has deep roots in phenomenology. Sources for this analysis were diverse, ranging from philosophical phenomenological work to concrete existential and sociological studies. I have chosen to spare the reader much of the theoretical and methodological detail of phenomenological philosophy, because phenomenological approaches often expire on the doorstep with detailed discussions of method that obstruct a passage to the very phenomena they tout. This work is guided by the conviction that adhering to the phenomenological battle cry *to the things themselves* is best accomplished by keeping attention fixed on the phenomena in question. The ethical and practical significance of autonomy ultimately rests on its presence in the world of everyday life. Thus, pointing out autonomy's least well-known features seemed more important than discussing the methodological processes by which these features are made apparent. This work owes much to philosophical phenomenology as well as to the ethnographic work inspired by Alfred Schutz's program of a phenomenology of the social world (1967). If actual autonomy does provide a viable focus for ethical reflection, then perhaps this work will inspire bioethicists to give the phenomenology of the world of everyday life far greater attention in addressing problems in clinical ethics. This book is best regarded as a work on how to plan and conduct a visit to a new country rather than as a detailed travel guide. It sets out a framework for improving the care of elders in long-term care by highlighting the actual ways that autonomy is manifested by individuals needing chronic care.

Work on the present edition was facilitated by outstanding preparatory work done by Candice Kieffer, with the assistance of Barbara Workman, who scanned the first edition to provide a reliable basis for revision and transcribed my numerous attempts to express a point or develop an argument. Ray Klancar

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Frontmatter

[More information](#)

x **Preface**

cheerfully tracked down many references and performed a yeoman's task in proofreading the entire manuscript. Finally, Nate Stewart provided an updated review of recent philosophical work on autonomy. I am grateful for their dedicated help and to the many colleagues and audiences who have discussed my ideas about autonomy and long-term care over the last decade.

G.J.A.
Shaker Heights, Ohio
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