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# The Age of Supported Independence

Voices of In-home Care

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# Preface

This book is dedicated to people like Mr Perry whose anguish over his disabilities was such that he contemplated suicide; and Mrs Martin who laughed and cried as she recounted the experiences of receiving and recovering from a double amputation; of Mrs Jackson whose intelligence and vigour had led her to prominence in the community and who was desolate in her later years to find her experiences and knowledge dismissed by agencies and their care workers.

Family carers too have their own tales: of the tensions between caring for a parent while wanting to be with grandchildren; of Mrs Lee's problem of caring for a sick and demanding husband while others helped care for her own terminal cancer; of Mrs Barton's anguish of watching others care for her husband and getting it wrong. She sobbed in the Carers Circle that 'they won't listen to me, and he can't see to eat, and they don't feed him, and I have to go in to the ward and feed him.' Her husband's carers were unable to understand too that Mr Barton couldn't unwrap the sandwiches on his plate let alone see to eat them—and they reported him as 'not being hungry.'<sup>1</sup>

In this book we contest how society thinks about older people, especially those with frailties and vulnerabilities. Instead of the homogeneity, expressed as 'the elderly', which normally describes those of 65 and over, we offer a perspective of transition, of changes and differences in status and identity, as we focus on older people as they become more frail and vulnerable and move into increasing dependence.

*The Age of Supported Independence* offers a detailed view of significant changes experienced by older people and their families, as they face the frailties and disabilities which require formal care to remain at home. 'Challenging' is the best description of these later years, for older people, for the services they require to remain at home safely, and for their families to continue caring.

Remaining at home with care confronts the ideals of stability and continuity of both home and care, by challenging the identities of older people who face disruptions to their agency and autonomy in these later years. These senior citizens also

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<sup>1</sup> These instances are from Hale's work and writing (2000, 2006).

experience challenges to their feelings about their homes, their bodies, their relationships with family and friends, and their relationships with formal providers of health and care. To examine the changes which, to repeat, ‘challenge’ older people and their families, we use a secularised version of the classical rites of passage model. Ours is the first book to apply this concept fully, despite its being considered of use by many social gerontologists. The concept’s value lies, in the first place, in its holistic focus on transition and its grouping of spatial, temporal and relational changes which accompany the passage from independence to increasing dependence. Subsequently, the value lies in emphasizing a third stage, of ‘reconnection’, leading us to consider the situation of frail older people in terms of the wider society.

This concept of rites of passage has a further value in that it helps us identify a specific population who share a culture of ageing with disabilities at home and with care. We suggest these experiences lead to a distinct late-life stage, different from independence and from greater dependence. We describe this stage as one of ‘supported independence’ where remaining at home is intended to provide continuity and stability, but where living and coping with disabilities and receiving care presents a major disruption of this apparent stability.

Our conclusions recognise the critical necessity for considering how best to support, enable, or empower older people to maintain agency and autonomy. This, then, is the third stage suggested by the rites of passage model, of reconnection to the wider society, or perhaps, in our terms, maintaining interests and valued roles, and assuming a status of a valued identity in our society. We emphasise the role of in-home care work here, and offer other ideas to assist in fulfilling the wish of New Zealand and other governments to age-in-place successfully.

This perspective has emerged through the work and research of the authors in the field of ageing and health, and care at home. Beatrice Hale worked in the field of community development, with older people as a social worker, and as a volunteer coordinator, before completing her doctorate on ageing and home care. Patrick Barrett writes in his capacity as lecturer and researcher in health and policy issues, and has recently spent time at Aristotle University of Thessaloniki in Greece where he lectured on New Zealand social policy. Health policy specialist, Robin Gauld, who currently holds a Harkness Fellowship in America, studying American health and care systems, writes from his wide knowledge of New Zealand and American health issues.

The authors would like to acknowledge the help and support they received from their families, friends and colleagues. We owe special thanks to Andrew Parsloe for his meticulous work on the index.

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# Introduction: Stake in the Ground

We invite you to explore with us the conception of a new social category within the once considered homogeneous group, ‘older people’. We invite you to reflect on the situation of those older people who experience disability and who receive care and support at home. Such individuals sit between the full independence of the Third Age, those also described as the young old, and the dependence which necessitates institutional care.

With an increasingly ageing population there are growing numbers of older people with later onset disabilities who choose, or are encouraged, to remain at home, with care. These are revealed in new demographic categories in a number of countries, prompting the reflection that here we have a new social group, identified as a specific category by social statisticians.

There is, however, a danger in reducing vulnerable people to mere statistics in the demographic classification process, and in ignoring their lived experiences. There is also a serious risk in assuming that the reality of these lived experiences is derived from and maintained by the twin ideals of home and care.

The ideals of home and care evoke notions of warmth, familiarity, continuity and stability. Such an ideal permeates the ageing in place philosophy but as Twigg (2000) and Dalley (2002), among others, observe, the privacy of the home obscures many different situations. What takes place behind closed doors can be lonely, isolating, abusive, violent, and far from the ideal notions permeating ageing in place. The unspoken belief in remaining at home is that it is *the* place where the provision of support and care will best ensure wellbeing, comfort and safety. Thus, the assumption is that the cared-for individuals will continue to remain safely and comfortably in the familiar home environment to continue with their lives as they wish.

Our exploration of this time of life shows a somewhat different picture, one which reveals considerable challenges associated with the experience of advancing into receiving in-home care. Such a progression produces a series of not only physical, but also social and emotional disruptions, and not only for the older individual. Family members who become carers also experience their own significant disruptions as they move deeper into a caring role.

Given the number of people moving into in-home care, and the unique but shared experience of doing so, we suggest that this period of time be known as The Age