

SECTION 1

THE ART OF CAREGIVING: POLICIES AND SERVICES

Introduction

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During the twentieth century, the developed nations experienced significant gains in disease controls and the development of effective and accessible medications and interventions for a wide range of diseases, disorders, and disabilities. There have been significant advances in the emancipation of women and informed public-health measures and standards through universal education and training. This social revolution has been aided for forty years by accessible and increasingly effective means of fertility control, resulting in reduced fecundity during the young adult years and the enhanced general health and concomitant increase in life expectancy.

Throughout the industrialized countries, the expectation is of a longer life span to the late 70s for men and the low 80s for women. As well, more people aged 65 and over anticipate aging well rather than poorly with minimal serious morbidity or disability and remaining in their own home and community, able to pursue their older years as positively as possible.

In each of the three nations considered in this book, the picture is very similar. While more people are living to around or beyond four score years, and more women than men reach their older years, the number of people achieving a healthy and well older life increases over time. The burden of disease, of all known causes of mortality, morbidity, and disability accounts for a dramatic increased rate from the age of 70 years for both men and women.

During the past decade, recognition has emerged of the need to improve and expand on caregiving services and attempts are being made by governments to provide better and flexible improved home and community care systems that can alleviate the immediate and long-term burdens of caregiving. In the years ahead, governments must also find different ways to provide financial compensation for caregivers through tax relief, income support, and indexed pension benefits. In the coming years, it is predicted that fewer people will willingly take on the family-based caregiver role, especially as more mid-aged women continue in paid employment for longer periods of time. The questions raised are: Who will care in the future? Where and how will that care occur? How will that care be funded? What choices and options exist currently and in the future?

The four chapters in this section seek to address these major issues and provide illuminating examples of the challenges and opportunities that each nation faces. The choices that are examined include state care-provisions in Israel, consumer-driven care services in the United States, and residential care facilities in Australia. The final chapter explores the new demands on the education and training of formal-care providers from the perspective of Israel.

Iecovich examines the interface of family and state responsibility for the care of Israeli older people. This focus also has universal resonance for all countries, not least, for both Australia and the United States. The key traditional duty of care for aging parents' needs among family members (filial responsibility) is proposed as an expression of family solidarity and positive feelings of "giving back." Yet today's young and mid-aged populations perceive a weakening of filial ties and the sense of intergenerational responsibility with a concomitant expectation that the state should provide the necessary support for its older populations through the provision of formal services. In keeping with similar changes in Australia and the United States, governmental financing has shrunk, forcing a greater reliance on family care for elderly people at home.

Recent researchers and policymakers have proposed that care provisions should not be seen as a dichotomy but rather a continuum, with an integrated model of family care that is supplemented by state care when the needs of the elderly exceed the availability of the family and its resources. It is also revealed that attitudinal differences exist among the various ethnicities regarding what is deemed proper attitudes and practices. Thus, in the traditional groups (e.g., Arabs), care for the elderly and the disabled is regarded as the proper domain of the family; contemporary emancipated groups (e.g., Jews) regard the government as the required provider of care needs and services.

Who will be available to provide the necessary care within the family is a key issue. The rising divorce rate, increases in single-mother families, and greater workforce participation by women indicates that fewer female caregivers are or will be available compared with previous times. While the accepted tradition within Israeli society is that family care of the elderly is the societal norm,

exceeding that found in other European countries, the tension between family and state-responsibility acceptance remains.

Given the changing shape of population demographics, the “sandwich generation,” the mid-aged children of older parents, will not be available to sustain caregiving demands. Therefore, it is proposed that the adult grandchildren of future elderly people will be required to contribute to the care role. From the state’s perspective, while it is predicted that community care services will become more significant to caregiving, the older people who are expected to have greater disposable assets than the current older cohorts will be required to contribute more in order to purchase formal services. For the younger age groups, there should be schemes introduced of employer-based contributions for this purpose as well as tax incentives and long-term care insurance to enable workers to prepare for their own old age and the necessary needs in their later years. Two interesting suggestions to assist in overcoming the anticipated caregiver deficits are to mobilize and train long-term unemployed people and to increase the utilization of prepared volunteers.

The situation of caregiving in the United States, as analyzed by Benjamin, indicates that long-term care concerns receive a lower place on the government’s policy agenda, while public pensions and health insurance preoccupy many Americans. While informal, family-based care and agency-based care services provide the “twin pillars of support,” the reality is that families are a resource of diminishing viability due to a gradual reduction in the numbers of available and willing caregivers. As well, a range of dissatisfactions with agency services has been identified for some time.

An innovative alternative to both of these types of services is referred to as Consumer Directed Care (CDC) which provides greater control for the care recipients to self-direct the choices of caregiving services, the particular providers who attend, when, and where. There is not just one model of this innovative reversal of care provision where the recipient is the one determining what is received rather than an agency deciding what an individual requires and shall be given. At one end of the spectrum is a model of expanded decision making that involves no financial control; the other is of total control by the recipient who takes on the role of employer. A middle model provides for an agency to operate as a case manager, while, in consultation with the care recipient, services are arranged, worker eligibility, qualifications, capabilities, and probity checks are determined, and the extent of service hours and wages are determined. This interesting departure from the usual agency-based service common in most places has already appeared in different states in the United States, and in several European countries. There are several benefits from this initiative, not least being the empowerment and flexibility that emerges through tailoring services to an individual’s needs at any given time. A needed aspect is for research to be carried out on the experiences of consumers, the impact of such a service, and the true costs to both care recipient and the service providers before any definitive statements can be made about the

feasibility of this innovative development. The abiding issues of choice, the facilitating aspects for and barriers against it in the Australian residential care industry are the focus of the chapter provided by Tilse, Wilson, and Setterlund. The authors discuss consumer sovereignty, individuals' rights, and citizenship discourses in relation to making informed decisions about existing choices of entering and remaining in an aged-care facility. Three major options exist under the Aged Care Principles to emerge in recent years that increase consumer choices. These include a wider range of community care "packages" that provide alternatives to residential care, emerging policies of aging in place with security of tenure, and stated outcome standards regarding resident lifestyles underpinned by consumer rights and responsibilities.

While there is evidence of aging in place occurring to a greater level than previously with increased capacity for consumers to enter and remain in the home of choice, choices are still limited by few alternatives, especially for those with high care and specialized needs. As well, limitations remain in the capacity and willingness of consumers and their representatives to exercise their rights and participate in decision making. Part of this can be explained by the unchanging attitudes and beliefs of care workers toward the older person as able and entitled to self-determination, the practical task-focused approaches to care, the hierarchical nature of residence administration, and a still pervasive negative ageism.

These regulatory practices serve to constrain real choices for residents, families, and staff as not only are residential facilities places to live and work in but also now, a great emphasis is placed on the profit margins. For present barriers to true choice to be overcome, the authors argue for changes in a whole of community approach that will require different leadership styles in residential-care facilities. A key question concerns who will train the managers to achieve a democratic community-focused model of supported aged care. From the perspective of Israel, the final chapter by Galinsky examines the new demands on the education and training of workers for the aged-care industry. The author identifies that the "new" older person lives in their community for longer with a gradual onset in medical and social losses over time that lead to increasing levels of dependency (the compression and expansion of morbidity phenomena). The current system of formal care is outdated, based on earlier custodial models of care that do not meet the contemporary demands and expectations of today's elders, and therefore the training needs should be rethought and modernized.

Key concepts for consideration include the ways and means to maintain individuals' functional independence for as long as possible, the necessity of integrating and coordinating community services, and the provision of a multi-disciplinary team approach from medical, allied-health, and social disciplines that can more ably respond to and address the complex array of issues affecting people as they age.

To effect these changes, the training programs of medical and allied health personnel (e.g., aged-care workers, nurses, social workers, psychologists, occupational therapists, physiotherapists) should be exposed to enhanced curricula in psychosocial gerontology and geriatric medicine, with internships or fieldwork placements in community aged-care services and facilities and primary-care settings. These proposals are placed against a backdrop of fragmented, uncoordinated services that remain seriously underresourced in spite of the growth in the older-aged segments of the populations of these three countries. Clearly, the need for enhanced education and training programs is urgently required so that the aged-care and support workforce can meaningfully provide and respond to the changing expectations of older people. These issues are universally recognized in countries throughout the world as the aged-care sector has traditionally remained the “Cinderella” poor relation in most health-care systems. The care of frail elderly people has usually been undertaken by minimally trained people, the career path has been unclear, and the remuneration has been low. Thus, the attraction of keen and committed workers has been difficult to start and sustain over time. It is only during the present decade that recognition has been increasingly given to the complex nature of such care requirements which has seen the concomitant rise in education requirements.

The four chapters in this section concerned with “The Art of Caregiving: Policies and Services” have all identified common themes. These include emerging desires for empowerment and right to decision making and control by the older consumers themselves; the struggles by family members to continue to provide support for their older relatives by a gradually diminishing group of younger adults; and the increasing mismatch between the style of formal caregiving that is based on old traditional models of care and the different sort of older person needing a range of care *supports* that do not infantilize nor diminish their rights. The characteristics of the older persons that emerge in these chapters indicate desires for self-determination, a strong voice in what is provided and available, and demands for flexibility in the provision of services that can be adapted to the individual’s changing needs over time.

Interestingly, the gaps and shortfalls in services, practices, and attitudes among many in the industry of aging provisions are very similar across all three nations under consideration here and can be identified in many other countries. A pressing need is for an enlightened contemporary education and training of the current and future workforce. This requires a move towards a collaborative approach between consumers and workers to replace the paternal custodial model that is still apparent in many places and in several guises.