

Preface

Pat Armstrong

We have heard a great deal in recent years about the threat posed to our medical system by our “aging” population. For even longer, we have heard stories about the horrors of “being put in a home.” Care at home is offered as the primary solution, and there is little talk about how to make residential care a positive option and a place for dignified care. This book is about promoting that conversation.

It is also about addressing long-term facility care as a woman’s issue. Most of those who live in long-term care facilities are women, although more men have been joining them there in recent years as other kinds of institutional care are closed and as hospitals focus on narrowly defined acute care. Just as important, the overwhelming majority of those who work in residential care are women. Women are also the ones most likely to provide unpaid support in these facilities. Yet very little of the research and policy discussion on long-term care recognizes the importance of gender or of gender relations in long-term care facilities. This book brings a gender lens to the analysis.

In several ways, this collection is a result of the collaboration known as the Women and Health Care Reform Group. We are a multi-disciplinary group that investigates and advises on the effects of health care reforms on women as providers, decision-makers and users of health care systems. As part of the Women’s Health Contribution Program of Health Canada’s Bureau of Women’s Health and Gender Analysis, our mandate is to coordinate research on health care reform and to translate this research into policies and practices. In all our work, we explore the issues for women, always asking which women are affected in what ways.

One way we carry out this mandate is by organizing workshops to bring those employed in policy and research together with health care practitioners. These workshops help to develop a better understanding of what the issues are for women and how these issues can be addressed in ways that take differences among women into account. One of these workshops focused on designing long-term residential care with women in mind.

Participants were sent two background documents to promote a shared basis for discussion. The conceptual paper I wrote with PhD student Albert Banerjee, “Challenging Questions,” was intended to provoke debate and

encourage participants to confront the assumptions we make about long-term residential care. Albert also undertook an overview of long-term care facilities in Canada because there is no place to go to find such a description.

The workshop began with a public forum. Stockholm-based professor and researcher Marta Szebehely developed a portrait of eldercare in Sweden, suggesting a social model as an alternative approach to residential services. In Sweden, not only are most services publicly provided and such care defined as a right but, as she explains in her article here, the government is under pressure to develop a gender-based analysis of eldercare. By way of contrast, Sheila Neysmith, a professor at the University of Toronto, examined the challenging situation of women and long-term care in Canada's most populous province, Ontario, and her article in this volume extends the comparison.

The rest of the chapters began as panel presentations and were later further developed by the authors and/or by our editor Jane Springer, integrating aspects of the workshop discussion.

We wanted the workshop to move beyond specific practices to principles. Presenters were asked to set the stage for the development of strategies that take into account women as residents, as paid and unpaid care providers, as decision-makers and as family members. We encouraged the panelists to help us think about what, in relation to its physical, cultural and social environments, makes facility care good for residents and for their families and providers.

In this book, Evelyn Shapiro and Morgan Seeley, advocates of publicly funded long-term care, begin the discussion with an impassioned exposure of what happens in private residential facilities. Nicole Eshkakogan, an Alberta researcher, sets out Aboriginal women's and men's long-term care needs within the changing context of their lives.

Based on her expertise as a union researcher and policy director in British Columbia, Marcy Cohen focuses on what women workers need in order to provide care that treats residents with dignity and respect. Dick Moore, coordinator of an Older Lesbian, Gay, Bisexual and Transgender program in Toronto, shares promising strategies for taking the interests of LGBT communities into account. Drawing on her experience as part of a diverse group of women who have defined exactly the type of facility and programming they want in long-term care, Beverly Suek addresses the obstacles to planning for our own later years.

These articles are not intended as definitive pieces, setting out the perfect blueprint for care. Nor are they meant to make decisive interventions. Rather they are thought-provoking essays to stimulate us all to start designing long-term care with women in mind, to begin imagining and prepare to realize a place we would be willing to call home.

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Challenging Questions

Designing Long-Term Residential Care with Women in Mind

Pat Armstrong with Albert Banerjee

Long-term residential care in Canada exists in the shadows, largely invisible in the debates on health care reform and rarely considered from a gendered perspective.

The *Canada Health Act*, the legislation that sets out the principles for our public health system, does not mention such care. The Romanow Report on the future of health care in Canada (2002) barely does. A 2006 Canadian Institute for Health Information (CIHI) publication on facility-based long-term care talks about presenting “an emerging portrait of a little-known sector” (CIHI 2006: iii). With data on voluntary reports from 7 out of 71 residential care facilities in Nova Scotia, it provides a very limited snapshot of the Canadian population in such care. Whitney Berta and colleagues (2006) offer a more comprehensive view based on Statistics Canada’s annual national survey, the Residential Care Facilities Survey. They are able to produce a more complete picture of who owns and who resides in long-term care, showing the considerable variation across the country in the services provided. However, they are concerned that “policy around nature (sic) and quality of long-term care (LTC) for the future is virtually absent from the political agenda” (Berta et al. 2006: 176). It is not much of an issue for researchers, either. For example, while patient safety has become a major issue in hospitals, it has been largely ignored in long-term care (Castle et al. 2007). Nor has it received much attention at the international level. As the Organization for Economic Cooperation and Development points out, international estimates and profiles for long-term care are not well developed compared to other areas of public spending (Huber 2005). In short, long-term care is hardly at the centre of either research and data collection or policy debates.

Yet long-term care facilities are neither new nor destined for extinction in the near future. There have been such facilities in Canada for well over a century. They have primarily served the elderly but they also provide care for many younger people with severe disabilities. We can predict that the cultural mix of residents will change as the impact of immigration since the Second

World War plays out among the old (Statistics Canada 2007a). It is harder to predict the extent to which the post-war generation will need long-term care as the proportion of seniors in the population increases. Other factors, such as changes in marital practices and in fertility, greater geographical mobility and new technologies will also influence the profile of long-term care residents. But even with a considerable expansion in home care services, we can confidently predict that the demand for long-term residential care will not disappear in the near future. What is often called the “aging of the population” has not lacked for attention in policy circles. The focus, however, has been primarily on the costs rather than on the quality of care and on medical rather than on care needs. Disability, too, has received some policy attention in recent years, but almost all the attention has been on closing facilities rather than on the people who remain in such care.

We can also predict that gender will matter in long-term care, given that gender plays a role in all social relations and especially in care ones. Long-term care matters for women in particular because women account for the overwhelming majority of residents and of providers. Although federal government policy requires a gender-based analysis where appropriate, the Romanow report fails to provide it. Few of the other reports that focus on long-term care do either. The Canadian Institute for Health Information does note that women account for 71 percent of the residents in Nova Scotia long-term care facilities and that there are “three times more women than men in the 85 and older group” (CIHI 2006: 23). But the analysis stops there, without going on to explore any other aspects of gender in facility care or the factors that contribute to this distribution. For example, research from the United States indicating that men’s experiences and behaviour in long-term care differ from women’s suggests that the gender of residents is a relevant factor for analysis (Moss and Moss 2007).

Berta and colleagues look at staffing, but fail to even mention that women account for four out of five workers in these facilities and a significant proportion of the managers in long-term care (Armstrong, Armstrong and Scott-Dixon 2006). They also comment on the importance of “volunteer care” without considering the gendered nature of this volunteer care work and they have nothing to say about the gender of residents (Berta et al. 2006: 192). Yet research by Donna Baines (2004) shows that the unpaid labour in facilities is often provided by female workers who are also paid employees in that workplace. Such “volunteer” labour follows highly gendered lines, with men less likely than women to provide this unpaid overtime. Women are also much more likely than men to provide unpaid care to family and friends who live in facilities (Grant et al. 2004). Men do seem to be providing more care than in the past, especially to spouses, but they still lag behind women. And research in Quebec indicates that women may no longer be willing to take

responsibility for unpaid care for family and friends, suggesting there may be growing opposition to providing this unpaid care (Guberman et al. 2006). In any case, the majority of women are now in paid employment, making it difficult for them to take on additional unpaid care work that may be required in the future. In other words, even though we have enough research to show that gender matters in terms of residents, providers, families and decision-making, a gender analysis is usually absent from the limited data and policy debate on long-term care.

Why is long-term care so poorly documented, analyzed and debated in the policy realm? And why is gender largely ignored in much of the policy and in many of the research documents that are available? In setting out some suggested factors below, we seek to set the stage for challenging these factors and for thinking through alternative approaches in long-term residential care, or in what may also be called nursing or personal care homes.

Long-Term Care as Failure

As author, consultant and former professor Bruce Vladeck (2004: 2) puts it, long-term care is “something most people don’t like to talk about; denial and avoidance are powerful psychological phenomena, especially in a society eager to promote the fantasy that no one really ever has to grow old.” Such facilities, he says, have become institutions of last resort that emerge in response to problems in other social institutions (Vladeck 2003). While he is talking about the United States, it is equally the case in Canada and much the same thing could be said about long-term disability. Long-term care facilities are based on particular notions of care, of family, of individuals and of women. For the most part, LTC is riddled with notions of failure on the part of them all, even though these notions are rarely articulated and even more rarely linked. These are failures we would rather not think about.

In order to begin a discussion about what long-term residential care with women in mind would look like, it is important to unpack these notions and challenge some central assumptions. As Sylvia Tesh argued in the first edition of what has become a classic book (*Hidden Arguments: Political Ideology and Disease Prevention Policy*), we need to get these assumptions and “the politics out of hiding” before we can begin a process of transformation. Like the Romanow Report, Tesh holds that “we need public discussion about the values, beliefs, and ideologies with which scientists and policy-makers begin” (Tesh 1988: 6). Against this backdrop, it is possible to move towards the development of ideas and practices for long-term care in which it has its own mandate — not as a solution to failure, not as an institution of last resort, but as an essential, gender-sensitive public service responsive to diversity within caring communities.

Hidden Assumptions about Care

In medical care, success is about treatment and cure. And, increasingly, it is about cure in a short period of time. Drugs, surgery and technologies are the main methods defining treatment in care. Hospitals are places for such care, with recent reforms focused on reducing hospital stays as much as possible. Over the last two decades, we have seen hospitals become more narrowly defined in ways that exclude much of the chronic and rehabilitative care once provided in places called hospitals. Indeed, CIHI distinguishes hospital-based continuing care from hospital care by saying that the “goal of care may not be cure,” even though most of those admitted into continuing care stay less than three months (CIHI 2006: 2, 1).

This distinction is important for more than one reason. First, when people leave hospitals, they are now understood to be leaving the protection of the principles involved in the *Canada Health Act*. This lack of protection under the Act itself suggests that less value is attached to other forms of care and allows provinces/territories greater leeway in providing public services. Fees can be charged, means tests applied, services excluded and provincial/territorial barriers introduced. As soon as payment becomes a factor in access to care, women are more likely than men to be denied access because they are less likely to have paid jobs, because they earn less when they do work for pay, and because their paid jobs are less likely to come with supplementary health benefits or pensions. Moreover, women are less likely to remarry after a heterosexual marriage breaks down and therefore less likely to have a spouse to assist them financially in their old age. We have little information about what happens to women in old age who have been in same-sex relationships, but there are few reasons to believe they are better off financially than their heterosexual counterparts. Women often cannot afford the parts of care defined as extras, such as private rooms, or may not get in at all because only private rooms with extra costs are available or because their provincial government does not cover this care. These charges also reinforce differences among women, privileging those with access to financial resources.

Second, those who enter a long-term care facility are usually defined as beyond cure or significant improvement from medical methods and thus as a failure of medicine. As a resident told Rory Coughlan and Linda Ward, in their study of quality in long-term care in Ontario, “when you come in here, your former doctor gives up on you” (Coughlan and Ward 2007: 53). A majority of the people in these residential facilities have been labeled as having some form of dementia, itself often seen as incurable (CIHI 2006: 24). In fact, dementia combined with some other form of severe functional limitation seems increasingly to be a basic criterion for entry as it becomes harder to get into public residential care. This link with the other major neglected area in health services, namely mental health, may contribute to the

low value and invisibility attached to long-term residential care. The fact that people leave the facility only for what are increasingly very short periods of intervention in hospitals reinforces the cure/incurable distinction. That most leave when they die reinforces the notion of failure, given that in medicine death is often defined that way — as it is more generally in our society.

The people who live in long-term care facilities are called residents and the facility is called a residence or even a home, further distinguishing the facilities from hospitals. Yet the residents are categorized primarily in terms of medical diagnosis. And both funding and staffing are assessed in relation to these diagnoses (Berta et al. 2006). Physically, the facility often looks like a hospital and is usually modelled on the hierarchies in hospital care. Public funding is often limited to medical interventions, and residents are charged for the accommodation costs that are supposed to make a facility a home (Sawyer and Stephenson 2002 [1995]). Moreover, care is usually divided up into specific, time-limited tasks reflecting a notion of people as body parts, with usually little recognition of the emotional and social support residents need as part of their care. Instead, efficiency and effectiveness are measured mainly in terms of the speed and quantity of tasks completed. Quality of care measurements are primarily medical, assessing such clinically related aspects as bed sores, falls, incontinence and restraint use. At the same time, many of the regulations and rules are aimed only at preventing the worst forms of abuse rather than at promoting a supportive, homelike environment (Gass 2004). On the basis of their Ontario research on long-term care, Coughlan and Ward conclude that these measures “are often impoverished and abstracted from the processes involved in care delivery and the environment in which they often occur, and lacking both sociopsychological aspects and the voices of patients.” In contrast, the “residents understood ‘quality of care’ to be better defined as ‘quality of life’” (Coughlan and Ward 2007: 48). The residents’ definition seemed much closer to the notion of a residence or home than to practices based on medical measurements of quality.

There is a third reason for understanding the distinction between hospital and residential care facilities and the link to failure. Defining these services out of the main part of public medical care, and as an area where medicine can no longer succeed, has allowed provincial and territorial governments to promote long-term care provided by entrepreneurs searching for profit. Long-term care becomes defined as a service like any other, removing the claim to such care as a human right. This separation allows for the recent rapid development of residential care services that are for purchase, and that in most jurisdictions lack the kind of regulation applied to other care services. Although they do not receive direct public funding, they do not receive public scrutiny either. Equally important, they separate those with funding from those without, leaving only people with no alternative seeking

subsidized public care. It suggests a return to long-term care as poorhouses, houses where women dominate as a result of their lack of resources in old age.

Important here too is the notion that public health services have failed to be as efficient and effective as the private, for-profit sector and that competition will lead to better choice as well as to cheaper services. Such an assumption promotes competitive bidding for government care contracts, government payments to for-profit firms and the adoption within public facilities of practices taken from the for-profit sector. A host of research is starting to reveal problems with the assumption of for-profit superiority, as well as with the assumption that for-profit methods are appropriate for care. Staffing levels in for-profit facilities tend to be lower than in non-profit ones; more of the care is provided by those with the least formal training; hospital admissions are higher from these facilities and so are formal complaints. Competitive bidding may not only increase instability and promote the minimum of care but also reduce both voluntary sector participation and resident choice (Berta et al. 2006). Ownership and market principles also raise questions about decision-making and stability. With many large owners in the health-care field and managers responsible to shareholders, local control may well be lost. Stability too may be at risk because for-profit firms will close if their facility is no longer profitable (McKay 2003b; Cloutier-Fisher and Skinner 2006; McGrail et al. 2007; McGregor et al. 2005; Shapiro and Tate 1995).

There is an additional point to be made about the value put on medical intervention and the contrasting value attached to long-term care. Workers in hospitals are more highly valued than those in long-term care. This value difference is evident in their wages and benefits as well as in the extent of their formal training. According to Berta and colleagues, those living in long-term care need “high levels of daily personal care entailing supervision or assistance with activities of daily living, 24 hour nursing care or supervision, and a secure environment” (Berta et al. 2006: 177). The registered nurses and licensed practical nurses who work in long-term care usually meet the same educational requirements as nurses in hospitals and may even have specialized training in geriatric care. But they are usually paid less than their hospital counterparts (Armstrong and Laxer 2006). Most of the care, however, is provided by personal care providers, who may or may not have formal education and who are not well paid for the work. Many of them have credentials, and most have become highly skilled at their jobs through long experience (Armstrong and Daly 2004). The failure to require credentials and training, though, reflects the idea that assistance with daily living does not require many skills. Equally important, it is assumed any woman can do such work by virtue of being a woman and it is mainly women who

do the personal care work. Indeed, women make up a higher percentage of this workforce than they do in the overall health care sector. This is women caring for women, a factor that may also contribute to the value associated with the facilities, the residents and the workers.

The point is not that medical or clinical care should be eliminated from long-term care. Rather, it is that we need to explore the implications of the dominance of the medical model in our approach to long-term care. And we need to examine the relationship between this model and assumptions about gender, drawing out the consequences for the construction of care and care work within residences.

Hidden Assumptions about Families

Introducing a journal issue on family and aging, Francis Caro claims that “the emergence of public interventions to address special needs of elders can be traced to the limitations of families” (Caro 2006: 1). Similar claims are made about younger people in facility care. The implication is that families have failed, either because there is no one left or because they refuse to fulfill their obligations to provide care as families did in the past. In any case, it sets up public care as the last choice, a poor alternative. And what we usually mean by families is female relatives, although we do expect male spouses to do more than they did twenty years ago and do expect men to provide financial support. The notion of family failure can add to the guilt and concern women feel as relatives, as well as to the hesitation they have in considering sending their relatives into long-term care unless every other possibility is exhausted, including their own health. This, in turn, contributes to the notion of long-term care as a last resort. So does the kind of investigation that happens before someone is admitted to a public long-term care facility. You have to prove considerable need and, increasingly, no family alternative before you are allowed public support for long-term residential care.

Yet the claim that families, and the women in them, now fail in comparison to the past does not stand up to scrutiny (Armstrong and Kitts 2004). There is a long history of paid providers in private households and plenty of evidence that people went without care. We have no strong evidence that most families or even the women in them have throughout history provided the kinds of care required in long-term facilities today. Nor do we have much evidence on the quality of care that was provided in families and by women. We mainly assume it was adequate, without investigation. Adequacy seems to be defined as what women did to provide care, whatever that was, and it was assumed that everyone lived in families with women who could provide care. The assumption that women are not providing the kind of care their mothers did for the elderly and disabled in the past is largely without basis in the research.

Moreover, there are several important differences between the current situation and that in the past. A much higher proportion of the population is surviving with severe functional limitations, and a significantly greater proportion of the population is living into very old age, thus increasing the demand on families for care. Sophisticated medical techniques can now be used in the home, permitting the kinds of care there that were never possible in the past. The fertility rate has fallen and family members are more geographically mobile, leaving fewer children to provide care for those with high needs. Divorce is more common and more women than men are left without partners in their old age. In the past, many women died at an early age from childbirth and thus fewer lived to need long-term care. The majority of women have now joined the majority of men in the labour force and most of their adult children have paid jobs. Both women and men work for similar reasons, even though women still retain the primary responsibility for domestic tasks. This leaves few people at home to provide more complex care, except for other people who are elderly or disabled and who often have their own heavy care needs.

Nevertheless, there is little evidence to suggest families in general, or women in particular, have abandoned their relatives and sent them into long-term care as the demands on their time and for their care labour increase. Rather, there is plenty of evidence that women have sacrificed their own health and labour force careers to provide long-term care and to avoid sending their relatives into facilities. There has been no growth in the proportion of the elderly and severely disabled in residential long-term care, even though their numbers have increased significantly and public services have been withdrawn. As women, and some men, make these sacrifices to provide care, they further reinforce the notion that residential, public care is the last resort.

Nor is there evidence that women fail to provide care once their relatives become residents in long-term facilities. Research from Quebec suggests that both women and men remain committed to supporting family members who need care, and that this is particularly the case for spouses. Perhaps surprisingly, people between the ages of 18 and 30 felt more strongly about family responsibility than older respondents (Guberman et al. 2006). This may bode well for the future. Nevertheless, this research also suggests that all age groups and both women and men are open to formal services. Their support does not necessarily mean they want to provide direct, personal care. Within Canada, there are cultural variations in the extent to which women and other family members say they are committed to provide long-term care for their relatives, although there is less variation in the actual care provided. There are also class variations in the extent to which families in general and women in particular can support their relatives by paying for care. In all