Eldercare–On the Auction Block

Alberta families pay the price

By
Wendy Armstrong
The Alberta Chapter
Consumers' Association of Canada

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The Alberta Chapter of the Consumers' Association of Canada is a provincially incorporated non-profit consumer watchdog group. It is committed to enhancing the quality of life for Alberta families by providing information, skills and strategies; analysing consumer problems; championing the rights of consumers and citizens to fair and honest dealing; and uniting consumers to ensure fairness in the marketplace. Funds are raised through memberships, donations, and project grants.

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Executive Summary

Since the 1990s, dramatic changes to Alberta's long term care sector have unfolded with little media notice. Confusing jargon, mixed messages, lack of data, and widespread differences among the province's 17 regional health authorities have disguised much of the restructuring. Yet the changes have not gone unnoticed by families. Today, more and more adult children and elderly spouses are finding themselves trapped in the bewildering grip of Alberta's heavily privatized LTC environment. What they find is rarely what they expect - or need.

In 2002 the Alberta Chapter of the Consumers' Association of Canada decided to investigate these changes. Our research found that both residential and in-home care for the elderly have become costly and inaccessible arenas for many people. Quality is often grim, staffing levels are marginal. The promise of innovative models of care has been largely eclipsed by limited access and decreasing coverage of the costs associated with care. Many families now face an untenable choice: either give up a salary to care for a loved one at home, or spend savings and assets to purchase private services. Indeed, so much of the burden and cost of care has been offloaded to families that the Long Term Care Association of Alberta is quietly advising people to purchase private LTC insurance to protect their income and assets.

If this sounds like American-style health care, it is. And just as the administrative costs of the U.S. system are much more expensive than Canada's, Alberta is now spending more money managing an increasingly fragmented LTC sector, leaving less money for actual care. Between 1997/1998 and 1999/2000, the actual money spent on administration by regional health authorities increased by 15.2 percent - more than for any other identified category except research and education.*

Background

Alberta began cutting public coverage of LTC in the early 1990s, first in the name of deficit reduction, then in the name of tax cuts to encourage business to fill the void. Construction of new nursing homes and auxiliary hospitals ceased. Between 1988 and 1998, acute care hospital beds dropped from over 14,000 to 6,300. Existing LTC beds were used to deal with the acute care shortage; as a result traditional LTC clientele were turned away and many terminally ill cancer patients found themselves paying per diem charges. Long-promised home supports never materialized.

The reduction in public LTC options created a large gap between what was needed and what was available to Alberta seniors. This gap, in turn, created immense opportunities for real estate investors. Developers imported a new retirement housing concept from the United States called "Assisted Living." These complexes bore little resemblance to the Assisted Living model pioneered in Oregon in the late1980s. Originally, Assisted Living was a progressive approach to caring for seniors and other persons with limited abilities. The model called for a home-like setting that gave residents control over their private space and enabled them to maintain their capacity for self-care. The program could also include a basic package of meals, housekeeping, and help with personal care; it could also offer the option to add on extra services.

* See End-note [25]

In Alberta today, the term Assisted Living usually refers to multi-unit apartments with varying amounts of on-site personal supports and care - all available for a hefty price. The original vision has been co-opted by commercial interests. Residents are often vulnerable due to their physical and cognitive limitations, yet the province says it has no responsibilities for licensing, tracking, or monitoring these facilities.

Faced with a severe shortage of public LTC beds, some Alberta health authorities are resorting to a new hybrid model, often referred to as "Designated Assisted Living". The health authority contracts with housing owner/operators for access to living units; the contract also covers access to 24-hour personal care, provided by the operator. Seniors placed in these units are responsible for the largely unregulated price of their lodging, food, utilities, and many other support expenses. Designated Assisted Living is part of Alberta's overall strategy of unbundling and offloading the costs normally associated with long term care.

Key concepts behind the changes

The alterations to Alberta's LTC environment were based on several key inter-related concepts

- **Distinguishing between "core" and "complementary" services**: Theoretically, this distinction would enable the public healthcare system to save money by limiting the number of services it covers (i.e., core services). Clinics, hospitals, and nursing homes would then be free to earn extra income by selling related services or products at unregulated prices (i.e., complementary services).
- **Separating "health" from "housing:"** Alberta has gradually limited its LTC funding obligation to a very narrow range of direct healthcare services, while withdrawing from support costs such as housing, meals, housekeeping, maintenance, utilities, and so on.
- **The level playing field:** This means making seniors in LTC facilities bear the same costs as seniors at home. In other words, if a senior in their own home pays for drugs, personal care, medical devices, incontinence supplies, housing, meals, and other costs of living, they would also pay for these in a LTC setting. In reality, level playing field means dragging public coverage of residential care down to the ever-declining level of home care.
- **Unbundling services**: Unbundling is the process used to operationalize the concepts above. The more a service can be broken down into its component parts, the more opportunities for reducing the basic healthcare package, contracting out services, and offloading costs to individuals and families. Not only can healthcare be unbundled from housing, but housing and support services can be atomized and unbundled further.

A number of false assumptions, unsupported by the evidence, regarding the merits of pursuing these policies have also fuelled many changes. These include perceptions about the wealth of seniors and their adult children, the affordability of private care and private insurance, and the costs to society from pursuing these strategies.

Conclusion and Recommendations

Alberta families are increasingly trapped in a high-priced LTC market with few real choices. Worse still, the battered public sector has adopted many of the expensive habits of risk-adverse private insurers, driving up the costs of administration and leaving less money for care. Since failure to address this situation will have grave ramifications for Alberta families, employers and communities, the **Consumers' Association recommends that the province of Alberta:**

- **Restore and expand universal public coverage for long term care supports, regardless of the setting.** Ensuring timely and affordable access to a wide range of quality public LTC services is an essential step Alberta can take to enhance the determinants of health among the elderly and their families.

- **End the unbundling of services.** Efforts should be made to re-integrate services, functions, organizations, and payments. Not only will this benefit individuals and families in need, it will also reduce administrative costs and maximize opportunities for wholesale purchasing.

- **Ensure full disclosure about LTC services.** Albertans have a right to open and complete information about availability and eligibility requirements for LTC services and about the costs and obligations of agencies and operators supplying services. Without this information, Alberta families and communities cannot make responsible choices or hold suppliers and plan administrators accountable.

- **License, regulate, and monitor supportive housing and Assisted Living settings.** At a minimum, supportive housing and Assisted Living operators should be licensed regardless of their ownership status. Formal and informal complaint and appeal mechanisms need to be visible and effective, and community groups should be supported to take an active role in acting as advocates.

Introduction

In the 1990s the province of Alberta undertook dramatic changes to the organization and funding of the public healthcare system. During the same period the Alberta Chapter of the Consumers' Association of Canada (CAC) played a pivotal role in monitoring the impact of those changes. The association recently turned its attention to the long term care needs of elderly people whose ability to care for themselves and live independently has been compromised by deteriorating health. This paper covers the highlights of our research. While our focus was primarily on services for the elderly and their families, most of our findings are also relevant to younger Albertans with chronic care needs.

Why is long term care a consumer issue? Simply because the direct and indirect costs of ill health can have such an unparalleled impact on the sustainability and financial, emotional, and physical health of families and communities. In particular, individuals and families of those requiring long term care (LTC) face enormous stress, suffering, and potentially ruinous expense in the absence of appropriate and affordable care options.

Our research shows that residential LTC in Alberta has become a very costly and ofttimes inaccessible arena for many people. Many families have been left with an untenable choice: give up a family income to care for a loved one, or purchase needed care in new U.S. style Assisted Living facilities - at U.S. prices. Individuals and families requiring LTC services are unclear about what, exactly, is available - especially from the province's new residential care models. The public system is rapidly "unbundling" services, which greatly fragments and reduces the scope of public coverage. At the same time, health authorities are spending more money administering an increasingly disintegrated and privatized system, and less money funding and delivering health services.

To help make sense of the situation, this paper looks at:

- **Step-by-step changes in the 1990s that shifted the cost and burden of care to individuals and families.**
- **The promise and the reality of changes in long term care, notably Assisted Living.**
- **The false assumptions driving many of these changes, including the role of the marketplace and the cost benefits of private-pay health care.**

To begin, though, a brief description of some research challenges.

Missing data: Accessing data is a real challenge in Alberta. When the province delegated responsibilities to 17 appointed regional health authorities (1995) and moved to population-based funding (1997-98), provincial data regarding numbers and categories almost disappeared. Lack of relevant and comparable data is a frequent theme in reports of the Alberta Auditor General. It has also limited the reliability of Canadian Institute for Health Information studies and created obstacles for academic-based researchers.

Confusing language: The language used in long term care reforms is often unclear. How the language is used is sometimes deceptive. Much is implied, but little is revealed. Concepts are complex and nomenclature is constantly changing. There are widespread regional variations and no official definitions. Comforting phrases such as "aging in place" and "taking care to the patient instead of the patient to the care" often have very different connotations than people expect. This paper attempts to disentangle the language and shed light on some of the mixed messages, hidden meanings, and broad themes surrounding healthcare reform in Alberta.

Long term care in Alberta before 1990

Before 1990, the province had three main options for seniors' residential care, two within the public healthcare sector and one in the housing sector:

Auxiliary hospitals were created in 1959 as a lower-cost alternative to acute care hospitals for patients requiring lengthy convalescence, rehabilitation, or permanent custodial care. Although part of the hospital system, elderly residents in permanent care were charged a token per diem in relation to the standard federal pension income, based on the rationale that these facilities replaced the resident's primary residence.

Nursing homes were brought into the system in 1964 to provide a somewhat lower level of care than auxiliary hospitals. Operators of private enterprise facilities, charitable homes, and new publicly owned homes were given access to public dollars, subject to regulations and standards. From 1967 to 1976 the province restricted the growth of private enterprise nursing homes, particularly by large out-of-province chains, due to concerns that the profit motive might adversely affect the quality of care and reduce opportunities for more integrated and cost-effective services.[1]

Public lodges, established in 1959, were a mode of publicly subsidized supportive housing outside the healthcare sector. Unique to Alberta, these public lodges were created to provide safe housing, nutritious meals, social opportunities, and minimal protective oversight by non-medical staff for independent but frail elderly people with minor health problems and limited incomes. Without such supports, these individuals were seen to be at risk for health breakdowns and hospitalization. Public lodges are run by community-based, non-profit foundations that also control entry; funding from resident rents, the province, and municipalities.

Alberta's LTC landscape before 1990 also included a small number of private homes that would take in seniors in rural settings, and smaller number of more expensive private lodges, primarily in large urban centres. A public home care program was established in 1978 to provide nursing and homemaking services to seniors in their homes and lodges.

Some planned changes to this traditional long term care environment were already in the wind in 1988, but it wasn't until the early 1990s that these changes began to be implemented.

Mixed messages behind changes in the 1990s

In the 1990s, dramatic changes unfolded in Alberta's long term care sector, accompanied by equally dramatic changes to the acute care sector. These changes were often "sold" to Albertans via several key messages that can be found in provincial government documents and media reports. The Alberta public was asked to support these changes because:

- Home Care and community programs are positive alternatives to institutional care.
- Increased reliance on families and friends is better for seniors (and at most a minor inconvenience). It is also a low-cost alternative to public care.
- Seniors will have better choices about where and how their needs are met.
- Services will be client focused, and seniors will be treated with respect and dignity.
- The government is taking "aggressive steps to prevent two-tiered healthcare."[2]

Yet these positive themes, often embraced by the public, were frequently accompanied by other messages that suggested quite a different story. These parallel messages stressed individual and family responsibility and the value of private markets. Albertans were repeatedly told that:

- Individuals and families are primarily responsible for their own health, with implied responsibility for the burden and costs of care.
- Consumers of continuing care services are well informed and capable of managing their own care. They also have more income and show an increased willing to pay.
- The buying and selling or private healthcare will stimulate the economy.
- Markets will regulate themselves for price and quality, so there is no need to interfere.
- The public can no longer afford to provide services to a growing number of seniors.
- Rising healthcare costs are due to abuse or inappropriate use, particularly by seniors.

As can be seen, these are two very different sets of messages with two very different sets of expectations. Unfortunately, the clearest trend in Alberta is towards reducing public coverage and encouraging new unregulated private-pay markets.

Disappearing care and coverage

The changes to Alberta's health system have been profound. For example, the number of acute care hospital beds dropped from over 14,000 in 1988 to 6,300 in 1998.[3] Many hospitals were closed or reclassified. Some were sold at fire-sale prices to private investors who would later contract with regions to provide desperately needed services.

Between 1989 and 1993, auxiliary hospitals and nursing homes were merged under one umbrella, despite significant differences in their original ownership and purpose. They were first labelled "long term care facilities" and then "continuing care centres." At the same time construction of new beds was halted and a new assessment process restricted access to high-needs residents only.

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In 1993 the Conservatives were re-elected under a new leader. Ralph Klein's government acted quickly on what they saw as their new mandate: deregulation, delegation, and increased reliance on private markets. The province sold off public assets and downsized public programs, first in the name of deficit reduction and later in the name of tax reductions to encourage private investors. Dramatic cuts were made to the health budget. Newly appointed regional health authorities were made responsible for both the provision of healthcare services and the health of the population in their area. Front-line staffing in LTC settings reportedly dropped in half.[4] Resident accommodation fees were increased, and the increase was sent to the Alberta Treasury to help pay off the deficit. Home care programs were overwhelmed by acute care demands after previous age restrictions were lifted in 1990/91 and hospital downsizing began in earnest in 1994.

In 1993 both the provincial and federal governments cut all grants for new subsidized seniors' housing. A year later, the province did away with several benefit programs for seniors that had helped maintain their disposable income and purchasing power. Eliminated were free health premiums and about $1,200 per year in rental or property tax supplements to help in Alberta's expensive housing market. Generous dental and vision benefits were substantially reduced and, ultimately, eliminated in 2002. Drug benefits decreased. In their place the province introduced a limited, income-tested Seniors Income Benefit Program.

Another significant event was the release of Alberta's 12 Public/Private Principles, a little-known document that emerged from the province's dispute with Ottawa over facility fees at private clinics. In this 1994 document, the province asserted two important principles: 1) an increased role for the private sector inside and outside the public healthcare system, and 2) the right of Albertans to purchase healthcare services "above their assessed need."

Taking Stock: Early evidence of the impacts

As the province rolled out changes, an array of problems surfaced throughout the system. Elderly patients were given little chance to recover in hospital; they were quickly shuffled off to LTC settings or their relatives were simply told to pick them up and take them home. Acute care hospitals began downloading new types of patients into LTC facilities. In-home care was limited. Families of individuals dying of cancer were dismayed to suddenly find themselves responsible for accommodation fees in LTC facilities or for substantial out-of-pocket expenses for care and supplies at home.[5]

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Patients recovering from surgery or medical treatment were increasingly admitted to new sub-acute and rehabilitation beds in traditional long term care facilities.

In 1995/96 the Consumers' Association decided to investigate the impact of these changes. We had initially championed many of the government's proposed healthcare reforms; now we wanted to determine exactly what was happening. The association established a toll-free number, did numerous interviews, documented people's actual experiences, and investigated many identified issues. We wanted to test the theory of reform against its practice.

The results of our research were shocking. Funding for services had not followed patients into their communities and home-based care. In fact, significant unanticipated costs had been shifted to patients and their families, including:

- major new expenses for drugs or drug co-payments, equipment, supplies, and transportation to healthcare professionals relating to in-home care.
- major direct and indirect costs to family members who took time off work to provide oversight and care; and
- patients being pushed into high-priced private-pay markets to purchase care

For example, patients with total hip replacements found themselves suddenly discharged from the hospital 3 to 5 days after surgery (compared with 10 to 14 days in previous years). Many individuals were unable to manage getting in and out of chairs, dress or undress, and prepare can meals. Fearful of going home alone or to a frail and elderly spouse, some patients would purchase a few extra days of convalescent care from a private nursing home for $100 or more per day.

The association also found that many expenses had been shifted to employer-sponsored benefit plans. Rather than providing full coverage to Albertans for community health services (formerly available in hospitals), the province would often only pay if the individual lacked a private benefit plan that could be convinced to pay. Individuals were also expected to pay substantial user fees based on their income and perceived ability to pay.

There were, in short, major gaps in public plan coverage and access to care. The Consumers' Association documented these and other findings in a report entitled *Taking Stock*

By the mid 1990s, deteriorating access to long term care beds, due to both the influx of new types of patients and overall population growth, led to excruciatingly long waits for placement in some regions and no choice among facilities for all practical purposes.[6] Meanwhile, real estate investors and private lodge operators were jumping into the vacuum with a new and expensive private-pay model imported from the U.S., which they loosely termed "Assisted Living".

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The Auditor General of Alberta finally sounded an alarm about the lack of LTC beds in his Annual Report. The 1999 Broda report, from a government advisory committee on long term care, simply reaffirmed the province's strategy of downloading traditional clientele into other settings and leaving families on their own.[7]

Due to the newly discovered uses for long term care beds as acute care beds, the province authorized the construction of 1,319 new nursing home beds. The government provided 25% of the capital funding, compelling health authorities to go into long term partnerships with the private sector to raise the majority of the money.

In order to understand some of the implications of the Broda report, it is important to decode the concepts used to advance Alberta policy directions in the last decade.

Decoding the jargon and concepts disguising the changes

Several key concepts have surfaced in Alberta's healthcare environment, concepts that play a significant role in how LTC issues are debated and acted upon, especially in the area of new public models of residential long term care called Supportive and Assisted Living.

Distinguishing between "core" and "complementary" services: The division of healthcare services into core and complementary categories emerged in the early 1990s. The theory behind core and complementary is that the public healthcare system will save money by limiting the number of services it pays for either in whole or in part (i.e., core services). Clinics, hospitals, doctors, and nursing homes will be free to earn extra income by selling related services or products at unregulated prices (i.e., complementary services).[8]

Take the example of laundry services in a publicly funded nursing home. Bed linen is laundered at no additional cost to the resident - it's a core service; but personal laundry must be paid for privately - it's a complementary service. If a resident wants to wear their own clothes (a recognized factor in maintaining health and well being), he or she is going to pay extra, and the price isn't regulated (about $25-$40 a month).

Basing access to care on "assessed need": Another concept from the early 1990s was that access to all publicly funded LTC beds or in-home care would be based on "assessed need" (i.e., assessed by a health professional from the health region, using a formal criteria). Most people don't realize that "assessed need" isn't what a person actually needs but refers only to the particular and often narrow range of supplies and services available through the regional health authority (RHA). In other words, an individual's assessed need is limited by what the regional home care program, for example, offers. The available services are more meagre than most people anticipate.

Assessed need has other problems too. Information about formal criteria and available services is not made public; in fact, wrestling this information from an RHA is almost impossible. Many seniors with disabilities are unaware of what they may be eligible for, in theory and in practice; even public lodge operators whose residents rely on home care programs talk about being perplexed.

Originally conceived as a process to ensure safety, fairness, and appropriateness based on professional judgment, "assessed need" is now often used to hide politically

embarrassing shortfalls, or undisclosed changes in the terms and conditions of public coverage.[9]

Separating "health" from "housing": In Alberta legislation, the per diem accommodation fees paid by residents in LTC facilities are acknowledged as a partial payment (co-payment) to cover the entire basket of room, board, and care services. In 1994, however, Alberta used an internal policy directive to move towards a different interpretation of this legislation. Today the per diem fee is construed as one that should eventually cover all costs of accommodation, including most of the costs of constructing and operating the facility.

This move was the beginning of a significant philosophical separation, designed to limit the funding obligations of the province to a very narrow range of direct healthcare services, with no obligation for support services such as accommodation, meals, housekeeping, maintenance, utilities, and so on. (These support costs are often called "hotel costs.") People may find it difficult to grasp the concept of separating the costs of services provided by healthcare personnel- be it wielding a scalpel or a washcloth – from the costs of the goods used to provide care or a special environment in which the service is provided. These elements seem inextricably linked. For example, most people would consider the meal provided by a worker to a LTC resident who cannot shop, prepare food, or eat without assistance to be part of their "care."[10] In fact, that meal is often deemed a housing cost in Alberta today.

The separation was designed to limit the funding obligations of the province to a very narrow range of direct healthcare services, with no obligation for accommodation, meals, housekeeping, maintenance, utilities, and so on.

The separation of healthcare from support and housing is an established trend. The shift to full personal responsibility for these costs is not yet evident in traditional facilities but is quite marked in Alberta's new models of residential care known collectively as supportive living.[11]

The level playing field argument: The most important new idea to grasp is the concept of the "level playing field," which gained momentum in the 1999 Broda Report.

In the 1990s one argument for moving care from hospitals to people's homes was that it would be substantially cheaper for the public system because the "hotel costs" would be transferred to the individual. Today, the level playing field means making individuals in LTC facilities bear the same costs as individuals in their own home, all in the name of fairness. The Broda Report put it this way: If goods and services were wholly or partially uninsured by the public plan in a senior's home, the

In other words, if you paid at home for drugs, personal care, medical devices, supplies, housing, meals, and other costs of living, you should also pay for these in a nursing home.

same goods and services should be uninsured in all settings. In other words, if you pay at home for drugs, personal care, medical devices, supplies, housing, meals, and other costs of living, you should also pay for these in an auxiliary hospital or nursing home.

Consider the example of intravenous therapy. In 1992/93 Alberta introduced an optional home intravenous program (the treatment had previously been restricted to in-patient settings). People had to pay 25 percent of equipment and supply costs and the first $5,000 of drugs (deductible) if they didn't have a private plan. Today, in-patient treatment is often not an option due to facility downsizing. Many patients are forced either to use the costly in-home option or to make frequent trips to outpatient departments for free therapy. But some hospitals and regions have been charging for this treatment based on the argument that it isn't fair that outpatients don't pay while people at home do.[12]

In reality, "level playing field" means dragging public coverage of residential care down to the low level of home care (while continuing to shrink home care programs). Alberta's position is a complete reversal of the more progressive idea of expanding public coverage of services in community-based settings.

Unbundling services: Unbundling is the process used to operationalize many of the concepts described above. The more a service can be broken down into its component parts, the more opportunities for reducing the basic healthcare package and offloading costs. Not only can healthcare be unbundled from housing, but housing and support services can also be atomized and unbundled further.

The components of continuing care services are now being subdivided into:

- access to information;
- professional case coordination and clinical services;
- personal care;
- technical supports (equipment, medication, transportation);
- residential supports (basic independence and enhanced independence); and
- housing (including capital and operating expenses).

Most of us think of care as a comprehensive whole. To use a metaphor, when someone buys a car, they expect it will come with tires, steering wheel, brake fluid, engine, doors, seats, etc. They can generally assume the car will be delivered in a complete and functional condition. People expect the same of residential care. An elderly person in a residential care facility needs ongoing case coordination (health monitoring). Perhaps they need clinical services such as dressings, and some personal care such as guidance with bathing, feeding, or incontinence care. They might need equipment, medications, or transportation to medical appointments, and residential supports such as meals, housekeeping, and laundry. Or they may require help with using a telephone, managing their pain or forgetfulness, their immobility and their fears. Some may require help with money management or someone to advocate on their behalf.

In the past, most of these services were inseparable parts of the healthcare basket. Today, they are being broken up and shunted into different boxes. Until recently, guiding a senior who was confused or having difficulty taking his or her medication would have been classified as a health professional service. Now it may be classified as a personal care service or an independence support provided by a housing operator.

The classification of services and products determines the personnel who arrange the service, provide the service, and bill for it at month's end. These divisions enable the costs of care to be shifted, bit-by-bit. For example, care aides have largely taken over responsibility for hands-on personal care for LTC clients. This development enabled health authorities to separate the tasks of personal care from the tasks of professional nursing, which in turn facilitated the contracting out of personal care to private agencies.

The unbundling trend also smoothed the way for the Broda Report's recommendation that people pay for all or part of their personal care (especially LTC clients). The rationale for this step is slippery: because people are normally responsible for their personal hygiene throughout their life, they should pay for their hygiene as they age (ignoring the fact they may be unable to do so due to a medical condition). This idea is supported by RHAs; personal care may well be the next service that Albertans are expected to pay for out of pocket.

Although promoted as a means of enhancing consumer choice, unbundling is little more than a consumer nightmare.

Although promoted as a means of enhancing consumer choice, unbundling - and rebundling with higher overall costs for the same basket of services - is little more than a consumer nightmare, financially and emotionally. The practice has allowed the province to continually erode coverage and transfer costs to individuals and families. Unbundling also drives up administrative costs significantly and compounds the complexity of evaluating services at a time when individuals and families are already overwhelmed.

A clear sign of the times comes from the Alberta Long Term Care Association. This trade association of traditional facility operators is quietly advising callers to consider purchasing. private LTC insurance to protect themselves, their income, and their assets.[13]

The news out of Alberta in the 1990s, however, was not all frightening. The last decade was also a period of innovation.

The promise of new public models of residential care

In the early 1990s, inspired by local and international research on aging, some public and not-for-profit LTC operators began seeking new and better approaches within Alberta's public system. After much lobbying, and with help of federal project money, they were able to pilot and evaluate three new models. These new approaches yielded many valuable ideas about alternatives to old-style facility care, yet their benefits were counterbalanced by the problem of unbundling "health" from "housing"

costs and the chasm between "core" and "complementary" services. The three pilots were:

- **An Assisted Living residence** in which 30 persons with limited nursing and care needs lived in a home-like setting that provided some health, recreation, and social services; with opportunities to purchase extra meals or housekeeping, and a commitment to aging in place.
- **A dementia facility** in which 36 persons with mid-stage Alzheimer's dementia were provided holistic care in a specially designed more home-like facility.
- **Adult family living programs** in which elderly persons lived in homes owned and operated by unrelated individual(s) who provided them with room and board; the owner/operators were paid for designated services.

The goal of these new models of care was to provide safe, compassionate, and caring environments; to keep residents connected to others and their past life; to create a home-like residence; and to reduce the medicalization of care so residents could maintain a sense of self and quality of life. An important criterion was that programs be client-focused and based on caring partnerships among staff, operators, and family members.

Between 1995 and 1998 the pilots were studied by a team of researchers from the University of Alberta, led by Dr. Norah Keating and Dr. Janet Fast of the Department of Human Ecology. The EPICC study sought to 1) describe the care giving partnerships in each setting, 2) determine the kind and amount of care/services provided by each partner; and 3) explore the attitudes of paid and unpaid partners towards the delivery of these services. To accomplish this, the researchers created a time-use tool to measure care activities such as enhancing well-being (emotional and social contacts), care management, financial management, transportation, shopping, housework, personal care, and skilled care.[14]

The partnerships appeared to be enhancing the well-being of residents

Overall, the EPICC study found a generally high level of satisfaction regarding quality of care. Many benefits were identified, and the partnerships appeared to be enhancing the well-being of residents. But the researchers also raised serious concerns about the demands on family and on staff, particularly where aging-in-place policies were involved.

Amount of care provided by family and staff: Researchers found that family members provided, on average, about 40 hours of direct services to residents per month (mainly enhancing care and transportation). Staff members spent about 100 hours per resident per month in direct services, although this varied substantially among the three models.

Pilot models of care **Hours of care per resident per month**		
	Staff	Family
Adult family living	152	32
Dementia care	93	34
Assisted Living	45	50

Source: EPICC

As the chart shows, Assisted Living can be a substantial load for family members. The EPICC researchers were particularly concerned that, if a senior hadn't purchased up to the next level of care in the Assisted Living setting, their relatives were forced to shop for groceries, make meals, and do extra housekeeping in addition to their ongoing social and emotional support. Family members reported feeling stressed, exhausted, and unable to take breaks or holidays. Researchers also expressed alarm over the social and economic well-being of the largely part-time staff and the sustainability of adult family living operators without additional resources. In Alberta, residents of adult family living homes are not eligible for public day programs or related transportation costs, leading to significant demands on individual operators.

The evaluation team's findings culminated in several valuable recommendations to improve the identified problems while keeping the benefits of these models. But by the time their report was released in 1998, the privatization die had been cast. The EPICC recommendations were ignored. Instead, the province and regional health authorities used the introduction of variations of these pilots to shift costs to residents and families, other government departments and municipalities.

Today the pilot models would be classified under the broad heading of supportive housing, which is one of three streams in Alberta's constantly evolving new LTC paradigm (the other two being individual homes and traditional LTC facilities). In this paradigm, Assisted Living represents the high-service end of the supportive housing stream. But, like the U.S., Assisted Living has branched off in many different directions in Alberta.

The many faces of Assisted Living: Alberta's new reality

Assisted Living refers to several different phenomena in Alberta. It can be:

- a philosophical approach to care
- a marketing tool for real estate agents - and buyer beware!
- new unregulated private nursing homes with "a la carte" care
- a cost-avoidance plan of the Alberta government

Let's take a closer look at these different faces of Assisted Living.

The original philosophy: The term "Assisted Living" refers to a model or care that recognizes the importance of caregiver approach and environment in enhancing the quality of life for people who are frail, disabled, or cognitively impaired. Developed in Oregon 15 years ago, it is based on six principles: choice, dignity, privacy of person and space, independence, individuality, and a homelike atmosphere. Assisted Living embodies the concepts of managed risk and bounded choices. For example, if a senior is unsteady on their feet, they will be supported by handrails, a barrier-free environment and someone watching from a distance rather than by chemical and physical restraints, even though they may be at risk for falling - if that is their agreed upon choice. The first public pilot evaluated by EPICC was based on this philosophical approach.

A marketing tool for real estate agents: Today the term "Assisted Living" is liberally used by real estate agents selling condominium and adult-living complexes. Originally the housing model of Assisted Living was as a form of supportive housing for independent seniors, largely built by churches and pension funds. These residences relieved seniors of home-maintenance responsibilities and gave them the opportunity to live in a secure building with neighbours of the same age and interests, while enjoying planned social activities and recreation. Some residences had optional dining room meals, housekeeping, a tuck shop, regular bus service, and beauty salons.

The contemporary market for so-called Assisted Living is a minefield of misleading advertising. Essentially, the term is being applied to residences that were formerly billed as "barrier free" or "adult living with amenities" or "on-site restaurant/dining room service." Very little by way of care or monitoring may be offered. Some for-profit operators promise a lot and deliver very little. For example, a highly promoted 24-hour security and health monitoring service may simply entail being handed a business card to call and order a private lifeline service.

Unregulated nursing homes with à la carte menus: These private lodges and retirement complexes offer a combination of safe and secure housing, hotel-type services such as regular meals and housekeeping, and nursing care (provided by personal care aides) - all for a hefty price. They are promoted as a residential option that falls somewhere between independent living and nursing home care.

Seniors can buy their own unit as a life lease, or they can be renters. For example, rents in one Edmonton complex go from $1,595 to $3,195 per month (2002). The facilities sell a range of services. Some have dining rooms only (no "room service"); others have 20- bed locked dementia units. Hotel-type services and personal care are purchased in separate units or in tiered packages, over and above basic housing costs. For example, one private facility charges:

Lunch (daily):	$196 per month
Dinner (daily):	$279 per month
Incontinence care:	$150 per month
Night checks:	$100 per month
Medication assistance:	$150 per month.

Assistance getting out of bed, dressed, bathed, or taken to meals is usually charged in 15- minute increments at $15-$28 per hour.

Profits flow to owners/investors from rents and from the sale of support and nursing services. In Alberta major players include the Reichmann family with their 70 percent ownership in Central Park Lodge Inc. and CPL Long Term Care Real Investment Trust. The field is dominated by real estate investors who usually contract out the management of on-site services. Several international and U.S. operators are eyeing the Canadian market, particularly for joint ventures with large Canadian developers.[15] Insurance companies are also investing. An advertisement in the *Edmonton Journal* in early 2002 invited potential investors to a seminar on how they could make a 20 percent return on Assisted Living condominiums.[16] The number of private units that bill themselves as Assisted Living is constantly climbing in Alberta, mainly in large urban areas. In 1990 Calgary had 400 such units; by 2001 there were 2,300 with another 2,000 in the planning stage.

Despite the high monthly costs, it isn't just rich people who live in these complexes. The crisis in access to public LTC facilities means that many middle-class seniors are forced to spend down their savings and cash in their assets to purchase the care they need. When they run out of funds, they are forced to move on. Desperate families will pay as much as $4,000 per month, or more, to place their parent in a private complex while awaiting a public LTC bed.

Private Retirement Living Complex
Life Lease (purchase)
Edmonton 2002

Bundled:

Homemaking Service (morning light housekeeping, bed making including weekly linen change, tidy counter, dishwashing, one load of personal laundry a week)	$150 month

Unbundled:

Weekly vacuum	$20 month
Laundry (one load per week)	$30 month
Health services:	
Medication administration assistance	$150 month
24-hour emergency monitoring	$40 month
(if call not emergency, an additional	$10 month
Daily telemonitoring	$30 month
Blood pressure check	
Weekly	$20
Monthly	$ 5
Blood sugar monitoring	$ 3 per check
Companion services	$15/hour
Meal escort service	$150 month
Bathing	$20 bath
Incontinent management (resident supplies product)	$150 month
Support stockings assistance	$100 month
Foot care	$20 month
Daily lunch	$177 $196 month
Daily dinner	$252 $279 month

Another private lodge (on rental basis) offers night checks ($100/month); help with support stockings ($100/month); oxygen management ($152/month); and services as listed above. The package deals for more dependent residents and dementia care cost $650 and $850 (respectively) on top of monthly rents from $1,595 to $3,150 (excluding meals and other amenities)

The chart entitled "Private Retirement Living Complex, Life Lease" shows the costs associated with some privately paid Assisted Living arrangements.

A cost-avoidance plan via "Designated Assisted Living": This last version of Assisted Living was indirectly documented in the 1999 Broda Report. Researchers from a consulting group identified opportunities for $145 million in savings (cost avoidance) for the province, essentially by shifting LTC candidates into settings where they bear more costs.

One particular method comes in the form of Designated Assisted Living (DAL). This is a hybrid model that appears to falls somewhere between the first public pilot of Assisted Living and the fully private pay commercial model. Here's how it works. A health authority contracts with private or nonprofit operators to control entry to a number of units in a lodge or housing complex; the contract also involves a basket of services including 24-hour access to personal care (up to $1,500 per month in Calgary, 2002).

Candidates are then placed in these units through the region's entry process - that is, if the person is able and willing to pay the "housing" and support costs set by the operator. Any additional care must be approved by a representative of the health authority. The catch is that the candidate must also be able to absorb additional expenses that would normally covered in traditional long term care settings. This includes co-payments for drugs and drug packaging, aides to daily living supplies, transportation, special equipment, and the package of "hotel" services such as meals and housekeeping. Usually, the more dependent the patient, the greater the need for supplies. While Regions reportedly try to find spaces for $900 to $1400 dollars, rents are not geared to income. In 2001 Calgary had 165 Designated Assisted Living spaces and Edmonton had 81.

The chart entitled "Designated Assisted Living Unit / Breakdown of Payment Responsibilities" demonstrates how the various components of care have been unbundled and shifted so that clients residents pay the same costs as they would in their own home (e.g. rent, drugs, bed linens, housekeeping, meals, building costs, etc.) The chart, taken from a request for proposals by Calgary's RHA in 2001, represents the high end of public support and care in Alberta today.

Designated Assisted Living Unit

Breakdown of Responsibility for Payment

Calgary Regional Health Authority, 2001

Resident payment responsibilities	**RHA payment responsibilities**
Accommodation charges • Rent • Utilities (client space only) • Cleaning (client space only) • Communal furnishings • Building maintenance costs (inc. capital expense)* • Meals (3) plus snacks • Linen laundry • Social/recreational activities • Administration of accommodation.	• Direct care support (i.e., personal care) • RN consultant on call • LPN on site 24 hours per day • Therapeutic recreational staff • Coordination of support services • Care supplies • Arranging transportation • Administering contract
Additional resident responsibilities	**Provided by RHA Home Care**
• Personal expenses • Personal laundry • Personal toiletries • Supplying linens • Telephone/cable in room • Drugs (co-pay Blue Cross) • Client room furnishings • Social expenses • Transportation costs • Personal insurance	• Professional case management • Professional care (e.g., RN and Rehab.)
Other Partners • Equipment (including special beds): co-payment with Alberta Aids to Daily Living program (AADL) • Drugs: co-payment with Blue Cross (if senior) AISH • Ambulance: co-payment with Blue Cross	

*The capital expense cost is new. In the past many LTC facilities were built with public money; today, privately constructed facilities pass their costs on to residents.

Operators are also free to sell additional services (see "Additional services" chart below) such as care from a Registered Nurse or personal care aide, special diets, and room service.

Additional services for purchase at a Designated Assisted Living unit (2001)

Personal Services

- Laundry or linen services
- Charges for second individual in suite
- Furnished suite
- Pet care
- Wheelchair or personal device maintenance
- Handyman services
- Additional housekeeping
- Transportation
- Special recreation & special events
- Craft supplies

Care Services

- Packages
- Companion Services
- Respite/Short Stay

Professional Health Services

- Registered Nurse
- Other (specify)
- Therapeutic massage

Meal and Food Services

- Special diets
- Room service
- Private dining room
- Visitor meals
- Additional meals

Source: Calgary RHA Request for Proposals

Many disabled elderly people simply cannot afford the housing and personal costs associated with these designated units. And while the RHAs' official statement is that no one is denied access to an appropriate setting due to lack of money, they privately admit quite another story:

> "The plan was to let the market set the price and the province would top up the people who couldn't pay," said one contact, "but [the province] seems to have forgotten the last part."

A stock of subsidized, affordable housing is desperately needed for low income seniors, yet Alberta faces chronic shortages. Under tremendous pressure, the RHAs have resorted to a two-pronged strategy: 1) using provincial social housing monies to build new Designated Assisted Living units to be run by non-profit organizations, and 2) trying to gain control over the public lodges to turn them into Assisted Living stock. Control over lodges, however, means squeezing out independent seniors who require only social supports, and would thus create a new gap.[17]

Consumer protection in new markets for care

Alberta has been starving public LTC facilities and home care, causing dramatic declines in quality and access, and leaving seniors and families with few places to turn. Desperate people are being forced to pay any price to get the care they need, whether through home care agencies, private lodges, or private Assisted Living developments.

Yet these Assisted Living complexes and other new models of supportive living used to replace traditional nursing home care operate for the most part, in a regulatory void. They are not licensed, tracked, or monitored except for the obligations/ monitoring imposed through RHA contracts. Given the terrible track record of the province and the RHAs in monitoring and enforcing quality standards in regular nursing homes, even this minimal oversight may not provide a lot of comfort.[18] Neither private pay facilities nor the housing/support services provided to assisted living clients outside an RHA contract are subject to the *Protection of Persons in Care Act.*

A senior's choice of housing is limited by the regional placement process and by their ability to pay - in other words, little choice for low or middle-income seniors. Any increases in publicly funded health services, which may be essential to prevent a person's loss of function, are restricted by the availability of an off-site regional case coordinator who may be unfamiliar with the client.

Assisted Living could easily regress to the state of yesterday's unregulated and often exploitive private care homes.

Definite limits exist regarding "aging in place". Residents and families may need to purchase substantial extra care for even temporary episodes of illness, or else face dislocation. Why? Because the minimal staffing levels and skill mix within these complexes make it difficult to provide significantly more support or two person transfers when required.

The promise of Assisted Living is in offering seniors the chance to maintain their independence in a personal domestic setting while receiving the care, social contacts, and attention they need. The original model was a dignified and responsive care option for individuals with chronic or declining conditions. But with Alberta's pattern of privatization and abandonment of the progressive public model, Assisted Living could easily regress to the state of yesterday's unregulated and often exploitive private care homes.

False assumptions challenged by the evidence

Alberta's long term care sector has been pushed and pulled by powerful and ofttimes competing forces over the years. Many measures have gone unchallenged due to the complex and camouflaged nature of the changes. Our research also revealed several widely promoted rationales used to justify new measures. When we examined the evidence, however, the justification for these claims simply did not exist. Let's take a closer look at three of these widely accepted, but completely false assumptions – or

myths, in fact – and the realities facing the next generation if we continue to allow these rationales to go unchallenged.

Myth #1: Today's seniors and their families are sophisticated consumers, willing and able to spend more for their care

Few Canadians can be called sophisticated consumers of LTC services. According to interviews with seniors' housing agencies, the savvy consumer of care housing doesn't exist. Residential care is not something people purchase repeatedly in their lives. The need for LTC services usually arises due to a major personal crisis such as a stroke, or the death or ill health of a care giving spouse. Families are often desperate. Evaluating complex service options is difficult and time-consuming, even with experience. The factors that matter most, such as quality of staff or integrity of the operator, are not readily visible or quantifiable.

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Purchasing healthcare services is even more daunting. Most residents are well into their 80s, and the incidence of cognitive problems related to dementia climbs significantly after age 85. How does anyone make a sound judgement about whether to buy a regular blood pressure check, particularly if an operator or nurse suggests they might benefit?

Essentially, the elderly must now buy their way into a housing situation to get the care they need, or have it paid, at least partially, by the public plan. But unlike at a hotel, seniors cannot just book themselves in because authorization is required from a health authority. Nor can they easily walk out, even from private-pay facilities: a change in residence can have a profound effect on the well-being of seniors with dementia, limited mobility, and shrinking social contacts.

According to a document from one RHA, seniors in need of care housing " have experienced health deterioration, and as such can no longer be supported in environments that are too demanding of their existing physical, psychological, social and emotional abilities." This certainly does not sound like a sophisticated consumer to us. Many relatively well residents in private pay facilities are even reluctant to complain when things go wrong for fear of being asked to leave.

Not necessarily wealthy: It is also a misconception that most people over age 65 are well to do. The median income of seniors in Alberta in 1997 was just over $1,400 per month.[19] The failure of private markets to provide affordable and appropriate rental housing for even independent seniors means that money from the sale of the family home can quickly disappear. Cuts to benefit programs and rising expenses have left many middle-class parents and grandparents struggling to hang on to their lifestyle; the situation of low-income families can be even worse. Loss of projected investment income is another problem for some middle-class households. Grown children are expected to fill the gap by either giving or buying care, yet are themselves often struggling to raise families. Many are only one pay cheque away from serious financial

problems. In the so-called land of plenty, Alberta families have the highest median debt load in Canada.[20]

Myth #2: Shifting the burden of care to families is costless to society

In fact, shifting the burden of care turns out to be substantially more expensive in personal, familial, and societal terms. Direct and indirect costs are borne by many parties: the recipients of care, informal family caregivers and their children and spouses, employers, and society at large.

The documented emotional costs to seniors include guilt, loss of control, anger, and loneliness. Loneliness because family caregivers often have little time or energy left over to provide important emotional and social supports when they are exhausted from the myriad tasks and responsibilities of hands-on care. Ironically, while a new emphasis on "client-centred care" is often used as a policy rationale to increase reliance on informal caregivers, studies suggest that elders themselves prefer formal paid caregivers.

The repercussions for spouses and children can also be significant: strained family ties due to forfeited income, lost family time, disrupted schedules, loss of privacy, and deterioration of marital relationships

For family members, the stress of constant caregiving often leads to emotional, financial, and health breakdowns. Out-of-pocket expenses are considerable, such as purchasing domestic services (yardwork, meals, babysitting) in order to "buy time," or purchasing private care. There are also the costs of lost work time, income, and future pension benefits if adult children are obliged to leave the work force. Some of these caregivers are destined to become the next generation of poor elderly. A U.S. study found that a so-called "career" of care giving costs an average of $656,000 in lost wages, pensions, and social security benefits, not to mention negative health impacts.[21]

. The repercussions for spouses and children of informal caregivers can also be significant: strained family ties due to forfeited income, lost family time, disrupted schedules, loss of privacy, and deterioration of marital relationships. [22] According to the University of Alberta Population Research Laboratory Surveys, there has been a major jump in the number of Albertans providing home or personal health support to a family member. The number of Albertans providing such care jumped from 31 percent in 1998 to 43 percent in 1999 and 46 percent in 2001. A significant proportion of these caregivers- 16 percent of women respondents and 11 percent of men- indicated that providing this support was a major disruption in their lives.

Employers of caregivers pay the price too. Family caregivers come in late, leave early, drop back to part-time, turn down promotions, choose early retirement, or give up work entirely. The 1997 MetLife Study of Employer Costs for Working Caregivers in the U.S. estimated that accommodations for working caregivers cost U.S. employers between $11.4 and $29 billion dollars per year in lost productivity not including the related healthcare costs to employer benefit plans. Ipsos-Reid's 2002 Canadian survey of employees with benefit plans found that about one third of respondents were taking

care of elderly family members to some degree, making it difficult for them to balance work and family responsibilities.[23]

Society at large also pays a price in lost tax revenues, higher poverty rates, family bankruptcies, and additional healthcare costs. In the U.S. over 500,000 bankruptcies per year are associated with healthcare costs, often LTC expenses. When a family unit loses its ability to be self-sustaining, social services must try to pick up the pieces. This is yet another reason why universal public health plans makes so much sense - paid for by the taxes of people who are well and working, so they have something to fall back on it when they are unwell.

Myth #3: Private pay markets and commercial suppliers will lead to lower prices for care and health plan coverage, and better value for money.

No evidence exists that increased reliance on private payment and commercial suppliers ensures better care or value for money. In fact, a substantial and growing body of evidence proves the opposite. Real competition, affordable prices, and quality controls are difficult to achieve in commercially driven health or care housing markets precisely due to the nature of the need, the high stakes, and the limited ability of someone to walk away to another supplier under the circumstances. Normal market forces do not exist. If the price of a bath doubles after someone moves in, are they going to shop for a bath elsewhere or change their whole social environment?

Private health insurance might be the poorest regulated consumer product in Canada. Policies for LTC insurance (residential and in-home care) first appeared in this country in 1995. The "market" is full of restrictions, financial and otherwise. Pre-existing conditions drive up premiums or preclude coverage. One policy we examined cost about $2,400 per year for an individual 50 years old (if approved for coverage); at age 60, premiums rose to over $7,000, depending on a number of variables. Lifetime maximums are in place. Shopping for health insurance may have even more pitfalls than shopping for Assisted Living.

Alberta's skyrocketing administrative costs: Relying on private insurance and multiple payers also adds enormous administrative costs. Prodigious amounts of time are spent evaluating risk and payment, determining eligibility and premiums, approving and processing claims, deciding who pays and how much, and selling policies. This fact helps explain an extremely important observation we made about Alberta's healthcare system. We had posed the question, "Why is Alberta's spending on healthcare at a record per capita high given the extensive off-loading of costs and reduction of benefits?" Here's what we found.

> Actual money spent on administration increased by 15.2% - more than for any other identified category except research and education

Intentionally or not, Alberta has created a high-priced American system of healthcare with widespread fragmentation of payers, providers, managers, and suppliers. In fact, the public healthcare system in Alberta, particularly for continuing care services, appears to have adopted all the features of the private insurer, multiple-payer

model that make U.S. healthcare spending the highest in the world. Why the high price? Significant new administrative costs.[24]

For example, the administrative costs of Alberta's RHAs rose from 5.6 to 6.2 percent of their total expenditures between 1997/1998 and 1999/2000. In contrast, spending on community and home based care only increased from 5.4 to 5.7 percent and spending on continuing care facilities dropped from 15.6 to 13.6 percent. Actual money spent on administration increased by 15.2% - more than for any other identified category except research and education.[25]

Comparisons to the U.S. healthcare system, where insurance companies run bureaucratized Health Maintenance Organizations (HMOs), are also striking. Staff in Alberta's 17 regional health authorities are spending ever-increasing amounts of time, energy, and money determining eligibility, evaluating, assessing, documenting, approving, coordinating, itemizing, billing, collecting, and arranging forever tinier unbundled units of care from multiple agencies-instead of delivering services. They are also constantly looking for someone else to pay. For instance, RNs are expected to fulfill the "cost-saving" role of denying care. (Alberta may be spending from $500-$1,000 to deny a bath assist). Using a regional care coordinator to evaluate and approve incremental units of care, rather than an on-site coordinator, also raises expenses.

Billing clerks are displacing RNs

In other words, many measures implemented in the name of saving money actually drive up costs.[26] Billing clerks are displacing RNs. The similarities to the claims adjudication process in the private insurance field are remarkable.

Wholesale savings abandoned for retail profits: Increased reliance on commercial suppliers and contracting-out also drives up costs. Historically, when private insurers in the U.S. first entered the managed care business (originally the domain of non-profits), they immediately bought up existing public and non-profit hospitals and home care businesses to bring their suppliers in-house in the name of cost savings. Alberta headed in the opposite direction. The provision of services has swung from in-house wholesale prices to retail pricing. The province seems to have forgotten the enormous benefits of wholesale prices, bulk purchasing, and internal flexibility - the original model of the Canadian healthcare system.

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Consider this example. People who need tube feeding for nutritional purposes usually purchase their monthly supplies from a retail pharmacy, paying about $400 per month for supplements alone. If a regional health authority purchases these supplies in bulk, the price drops to $100 per month. When Edmonton created such a public service

for individuals, retail pharmacists tried to scuttle the program out of concern for lost profits.

The rationale for creating regional management bodies was to increase the integration of healthcare services and reduce costs. Yet it appears that the entire continuing care system in Alberta has dis-integrated over the past decade, and both public and private costs are rapidly rising. Instead of moving ahead, Alberta is actually going backwards.

Conclusion

Policy makers across Canada are spending more and more time talking about how the determinants of health can improve the well-being of Canadians and hence reduce the pressures on medicare. In fact, the theme of keeping people healthy to avoid demands on the public system was a key feature of the Alberta Premier's Advisory Council on Health report, also called the Mazankowski Report (2001).

"Determinants of health" refers to factors known to have a powerful impact on the health and well-being of people within a society. The determinants include having a reliable and adequate income to purchase both the necessities and some pleasures of life; a decent place to live; and opportunities for social interactions. Other determinants involve having some control and choices in one's life, some personal privacy; and adequate nutrition, rest, and exercise. For those needing care and their informal caregivers, the constant strain of coping with scarce resources and juggling obligations are known to have a detrimental effect on their health, their use of health services, and their relationships with family members and employers. Undoubtedly, a significant determinant of health is access to a reliable network of LTC services that foster the wellness and sustainability of families.

Undoubtedly, a significant determinant of health is access to a reliable network of LTC services that foster the wellness and sustainability of families.

Although the Mazankowski Report paid lip service to keeping people healthy, it nevertheless recommended offloading more responsibilities to individuals and families, unbundling more goods and services, increasing use of commercial suppliers, and greater reliance on private-pay care options. According to the Advisory Council, such strategies are necessary to ensure the sustainability of the public healthcare system and plan coverage.

Yet the Consumer Association's research reveals that these very strategies are at the root of devastating changes to Alberta's LTC sector since the 1990s. The costs of care have been offloaded to individuals and families. Services have been unbundled and fragmented in destructive ways. Both residential care and home care have witnessed the concentrated growth of profit-oriented suppliers. Families have been railroaded into new private-pay markets due to decreased public access and quality.

Rather than fortifying the public system, Alberta's strategies have compromised the sustainability of the public system. Excessive fragmentation of LTC services has driven up administrative costs, leaving fewer dollars for actual care. It has also driven

up the private costs of care. If trends continue, it is possible that in some not-too-distant future the only services covered by the public plan may be the claims adjudication process by regional care coordinators, clinical services by professionals, and Medicaid-style provisions for the truly destitute.

In the early 1990s Alberta was not alone in altering its approach to healthcare and eldercare supports; the federal government and other provincial governments have also been guilty of shifting the burden and costs of care. If provincial and federal policy makers are truly committed to sustaining families and communities by improving the determinants of health, regressive policies that shift the burden of care and costs and drive up prices must be reversed. With families scattered across many provinces, this is clearly a national problem.

Recommendations

- **Restore and expand universal public coverage for long term care supports, regardless of the setting.** Ensuring timely and affordable access to a wide range of quality public LTC services is an essential step Alberta can take to enhance the determinants of health among the elderly and their families.
- **End the unbundling of services.** Efforts should be made to re-integrate services, functions, organizations, and payments. Not only will this benefit individuals and families in need, it will also reduce administrative costs and maximize opportunities for wholesale purchasing.
- **Ensure full disclosure about LTC services.** Albertans have a right to open and complete information about availability and eligibility requirements for LTC services and about the costs and obligations of agencies and operators supplying services. Without this information, Alberta families and communities cannot make responsible choices or hold suppliers and plan administrators accountable.
- **License, regulate, and monitor supportive housing and Assisted Living settings.** At a minimum, supportive housing and Assisted Living operators should be licensed regardless of their ownership status. Formal and informal complaint and appeal mechanisms need to be visible and effective, and community groups should be supported to take an active role in acting as advocates.

Endnotes

[1] Ministerial Briefing Memo to the Hon. Neil Crawford, 1973, Selected Minutes of Nursing Home Committee Meetings, 1970s, Alberta Health Library.

[2] Advertisement by the Government of Alberta, *National Post*, September 9, 2001

[3] Alberta Health Annual Report, 1988, and the Canada Health Act Annual Report, 1988-1999.

[4] Based on interviews with managers and front-line staff.

[5] In 1995 a palliative care doctor in Edmonton advised a Committee of the Alberta Medical Association that "in 1992-93, 85% of patients who died of cancer in Alberta, died in acute care hospitals. In 1995-96, it is expected that 70% of patients who die from cancer will die at home or in a long term care facility." *(Taking Stock*, Alberta Consumers' Association, 1996).

[6] In fact, in order to get "placed", families must go on an urgent waiting list and take the first bed available. While later transfers from within the system are an option, the trauma of readjustment means many don't bother.

[7] The Broda Report's official title is *Healthy Aging: New Directions for Care.* It was the report of the Long Term Care Policy Advisory Committee issued in November 1999. This committee was struck in 1997; its research was commissioned in 1998 and included a review by KPMG.

[8] This split was heavily promoted by commercial operators as a means for them to provide a lower contracted price to the public plan while maintaining profit margins and patient access to valued (or marketed) services. *Canada's Canary in the Mine Shaft*, Alberta Consumers' Association, 2000.

[9] Frustrated families and outreach agencies complain that requests for information are met with a response that the individual "will receive whatever they need to meet their assessed need." Yet when services or placement is obtained, it often doesn't meet their needs at all. Numerous families have reported their unhappiness with what appears to be a commonly assessed need for all LTC residents: one bath per week.

[10] This separation also means that, although resident fees continue to rise, the money cannot be used to increase the level of hands-on caregiving.

[11] This strategy is not unfamiliar to the Alberta government; it reflects the province's position on facility fees charged by private cataract clinics until 1996. Since the first clinic opened in 1980, the province maintained a position that its only obligation was to fund the doctor's professional fee, not the operating costs of the facility. This left patients to cover the full operating costs and any profit desired by operators, over and above what the surgeon billed to the public plan. (*The Consumer Experience with Cataract Surgery and Private Clinics in Alberta: Canada's Canary in the Mine Shaft*, Consumers' Association of Canada, 2002).

[12] A 1998 consultant's report to Alberta Health on the status of intravenous treatments went so far as to suggest that regions and hospitals that do *not* charge outpatients are misinterpreting stated restrictions in both the *Alberta Hospitals Act* and the *Canada Health Act*. The report argues that such charges are only restricted if the service is exclusively provided in a hospital setting out of necessity. C.A. MacDonald and Associates, *The Provision of Publicly Funded Drugs in Community Settings, Alberta Health,* February 1998.

[13] Interview in 2002 with Dianne Mirosh, executive director of the Long Term Care Association of Alberta.

[14] EPICC, the acronym for Evaluating Programs of Innovative Continuing Care, was an interdisciplinary research project conducted between 1995-1998. Dr. Norah Keating, of the Department of Human Ecology, University of Alberta, was principal investigator. The research was funded by Health Canada,

National Health Research and Development Program (NHRDP), through the Seniors' Independence Research Program (SIRP) and the research arm of Canada's Drug Strategy (CDS).

[15] *Globe and Mail*, "Seniors housing crisis predicted: Developers unprepared for boom: analyst," undated clipping, circa 2001, and Malcom, K., *The Financial Post*, "Seniors market pumps up: companies are scrambling to amass nursing home empires and cash in on growing number of golden oldies," undated clipping, 2002.

[16] Whitehorn Lodge, Assisted Living Condominiums promotional package, 2002.

[17] The loss of safe, affordable housing for independent seniors would be no small matter. The academic research is overwhelming: living alone on tea and toast is no way for an independent senior to stay healthy. If someone has inadequate income, inappropriate housing, no social contact, and difficulty buying groceries, a healthcare disaster is not far down the road. As well, the municipalities that provide substantial grants to public lodges, which are considered low- income housing, also question their taxpayers dollars being used for traditional nursing home clients.

[18] Documented in a publication called "The Shame of Canada's Nursing Homes" by a Calgary based organization called Families Allied to Influence Responsible Eldercare (FAIRE), and supported by feedback from another grassroots organization in central Alberta called Families Protecting Patients.

[19] *Alberta for All Ages: Directions for the Future: Alberta Community Development,* June 2000.

[20] Vanier Institute of the Family website.

[21] 1999 MetLife Juggling Act Study. Recent research suggests that mental or emotional strain experienced by the caregiver is an independent risk factor for mortality, particularly among elderly spousal caregivers of people with Alzheimer disease. Schulz, F. & Beach, S. (11999) Caregiving as a Risk Factor for Mortality: the Caregiver Health Effects Study. *Journal of American Medical Association*, 282 923), 2215-2218.

[22] Fast, J. Keating, N., Oakes, L. , Conceptualizing and Operationalizing the Costs of Informal Elder Care, NHRDP, 1997.

[23] Aventis Pharma, 2002.

[24] Harvard researchers found historic administrative costs in the U.S. to be four times greater than those in Canada. Another significant cost factor is fraud. While the U.S. Medicare and Medicaid Programs are busy taking numerous commercial suppliers of LTC services to court for fraud, Canadian policy makers appear to think the problems do not exist here. Yet regulation and monitoring will inevitably become part of a privatized LTC sector, driving costs up further.

[25] **Correction to original paragraph December 2002**. Sentence 3 in paragraph 3 of Executive Summary reflects correction. (Reference: *Is the Balance Right*, Premier's Advisory Council on Health, December, 2001)

[26] Calls for more private sector spending on health care are at odds with the fact that in 2000, Canada had one of the highest levels of per capita private funding for health care of all the OECD countries – ranking third after the U.S. and Switzerland. (*Every Number Tells a Story: A Review of Public and Private Health Expenditures and Revenues in Canada 1980 – 2000*, Conference Board of Canada, March 1999)

Appendix
Insights from the Front Lines

NEW TAX ON THE DYING

My father had been on palliative home care and Mom, 88 was terrified of him dying when she was alone. The nurse said he couldn't go to the hospital; he have to go to long term care. It was terrible – with no special treatment and no one seemed to notice when he was in pain. Mom got billed within days of his admission and had to pay a month in advance. I can still see the look or horror on her face when she saw the bill for over $1300 dollars and gasped "But I thought we had Medicare." Dad died 9 days later"

Family Member, CAC Alberta files, 1996

ASSESSED NEED FOR ALL LTC RESIDENTS: ONE BATH A WEEK: "We just don't get it until we're there. I never thought my mother who was so impeccable would actually smell. I can't believe the care she doesn't get at that nursing home."

Laurie, Edmonton, 2002

GETTING ANSWERS

"Many people often just need some help to get washed or dressed in the morning when they are ill or have problems after being in hospital – but it seems impossible to find out what someone is eligible for."

Outreach worker,
Edmonton Seniors Organization, 2002

WAREHOUSING

"The people who need the most care and are almost totally dependent get the least care. I call it 'warehousing'. These are people who are incontinent and can't dress or wash themselves, but they are still people too. Sometimes there is only one person for 10 or 15 people, and the quality of the care you get depends how far you are down the hall. If you are in the first room, you may be gotten up and washed at 5 o'clock in the morning, and if you are at the end of the hall, you can sleep in. But if you are at the end of the hall, you also have to wait the longest to get pottied."

Community Care Nurse
Southern Alberta, 2002

FILLING IN THE GAPS WITH TIME AND MONEY

"Many families either go in daily to feed a parent in long term care or pay someone to go in and feed them or they don't get fed.. One woman paid $10,000 per month at a private lodge to make sure her failing mother was fed and taken care of."

Bev McKay, Families Allied to Influence
Responsible Eldercare (FAIRE),2002

PUSHED INTO PRIVATE MARKETS: THE NEXT GENERATION OF POOR

"I finally got a call from the private lodge with a special 20 bed unit for people with dementia. It costs about $2340 a month, but it's going up another $200. Mom's been there well over a year now waiting for a public bed and I'm starting to worry. With her income, she'll have used up all her savings in 2 ½ years and then what will I do? I'm now starting to get a little worried about me. I wasn't able to work much all those years caring for Mom, and only make about $11 dollars an hour as a personal care aide myself. I thought I'd get at least a small inheritance, but now if I don't get a place soon, it's going to be all gone."

Daughter, 2002

BUYER BEWARE

"I've worked with a number of housing and assisted living buildings over the years, both for-profit and not-for-profit. It really depends on the owner/operators, their philosophy and if they are fully occupied or not. Some are good, and some really take advantage of people with add-on charges and unbundling everything from the basic rent. People need to be careful and not just read the brochures. But it is often a crisis, like the death of a spouse or some new health problem that will lead to them needing this kind of facility."

Nursing Consultant, Calgary, 2002

CHERRY PICKING

"We don't allow you to rent is if you can't get from point A to point B, if you have a wandering problem or anyone who needs attention on a regular basis such as someone with dementia or a brain injury. The R.N. on site comes with the building and residents are only charged if they need if they need a needle or a dressing change, doctors appointments. We also provide personal care or whatever service someone wants for a fee."

Manager, private assisted living complex

COMMERCIAL INTERESTS FOLLOW THE MONEY

"Private operators need 60-80-100 bed operations to make a go of it and rural Alberta just doesn't fit the bill."

Regional representative, rural RHA

CAPTIVE MARKET

"We just started something new with the Region where we get paid a "package" amount for providing services to some of our residents who are eligible for Home Care -– a kind of block funding. Yes, we are a little concerned that this will affect our returns on sales of services, but we're hoping that by providing some public services, people will be encouraged to top up. For example, the public home care program will only pay for one bath week if the person is continent and 2 baths per week if the person is incontinent. If people benefit and like the service, they may choose to purchase more, and baths assists cost $16 per hour." *Manager, private lodge*

SOPHISTICATED CONSUMERS

"I try to be up front with potential residents about the costs, but the marketing people sometimes get a little overzealous. It can be expensive and people need to think about these things, but they are usually in a crisis when they are making a decision and it isn't easy. We've had 2 people in their 90s who outlived their funds and had to move."

Nurse Manager, Private Assisted Living Residence

WHEN THE MONEY RUNS OUT

"Mom scrimped and saved all her life and did without many things so that she would never have to be in a nursing home or be a burden on her family. But with the low returns on her savings and paying for care only a few hours per day and three evenings a week for years, almost all her savings are gone. Home Care doesn't provide any help for people with dementia. She's now out of money and out of choice.

Daughter , 2001

NOT NECESSARILY WEALTHY

" Most of my clientele are retired people. Many of them coming to me wanting give up the hassle of home ownership, repairs and shovelling snow. They want to sell their house and move into a condominium or one of the new rental accommodations for seniors. When markets were treating us wonderfully this was economically viable to do so. But these days with the volatility of the market, the most you can get for a $165,000 tax paid capital investment from the sale of your home with a fully guaranteed investment is about 4.5% paid monthly. That's only about $619 dollars per month. After taxes they may be lucky to have $500 per month. Add to that the Old Age Security of about $500 per month, and any CPP earnings and its still not a lot, and it leads to people going through their assets very quickly. With a longer life expectation and little earning power, assets can disappear pretty quickly. I don't recommend that people sell their houses now. I encourage them to try and stay in their homes.

Gary Keiller, Financial Advisor,2002

TOLL ON CAREGIVERS HEALTH

"I can't believe it went on so long without any help. For months, I rarely saw my husband or my friends, and would only drop in to work to meet my most pressing obligations. I had some health problems of my own but not time to see a doctor. I was so emotionally drained and exhausted, I ended up taking another 4 months off work to deal with my own health problems."

Corinne, Edmonton, 2002

FAMILY BREAKDOWN

"Mom was incontinent and I couldn't go out anymore. She was getting harder and harder to handle, and my husband was getting frustrated because I could never go anywhere with him. It seemed that I did nothing but work and take care of Mom and all her health problems. I also really need to work more because we didn't have that much money."

Arlene, Calgary, 2002

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