Missing Pieces of the Shift to Home and Community Care:

A Case Study of the Conversion of an Alberta Nursing Home to a Designated Assisted Living Program

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1. Introduction

The landscape of continuing care services and settings in Alberta has changed considerably over the past decade, especially since the release of the 1999 *Healthy Aging: New Directions of Care* report – the "Broda Report". This report set the stage and direction for significant changes in the financing and delivery of health care services for Albertans with continuing care needs, particularly older Albertans. Its publication signaled a conscious decision by the Alberta government to begin a major shift from "institutional" to home and other community-based settings for long term care situations - with some significant consequences. In general, the *Canada Health Act* requires provincial health plans to cover all "medically necessary" care, but only if this care is provided in hospital settings or by a physician in the community.[1] Although provinces can and do extend coverage beyond this level, in practice, many care-related expenses outside hospital walls are either not covered, only partially covered, only covered for certain populations or only covered for a short period of time (i.e. "acute" home care). As a consequence, home care and community care is largely a private expense in many provinces, particularly for those who have long since retired and have no employer benefit plan to fill in some of the gaps.

In order to both reduce the burden on the public purse and enhance choice in location of care for the disabled elderly, the Broda Report recommended "unbundling" and reclassifying "health care" and "housing" services and further unbundling various components of care - shifting increased responsibilities to recipients of care and/or their families. Instead of extending universal needs-based coverage in public institutions to new community settings, it recommended that public coverage for all except a narrow range of continuing care services be based on demonstrated financial need and this new funding model be gradually harmonized across all care settings. Making public subsidies available for those unable pay the additional expense would ensure that no one would be denied access to basic continuing care services "because of an inability to pay."[2]

Since then, these recommendations (reinforced by the 2001 "Mazankowski" Report[3]) and a desire by many families to avoid the reported deteriorating conditions in traditional long term care facilities have led to many continuing care clients with high needs being admitted to new care housing alternatives, including Designated Assisted Living programs/settings. At the same time, traditional auxiliary hospitals and nursing homes in many Alberta communities are either being closed down or refurbished and used for other purposes, leading to limited access for traditional clientele. New Designated Assisted Living (DAL) arrangements are springing up in their place.[4] In these DAL settings, residents and families take on more responsibilities for arranging and paying for care supports and care-related expenses. To date, the extent and nature of these responsibilities have not been clear or well defined. The lack of a legislative framework and

[1] An exception is that Section 19.2 of the *CHA* allows "user charges for accommodation or meals provided to an in-patient who, in the opinion of the attending physician, requires chronic care and is more or less permanently resident in a hospital or other institution" without penalty to a province. Mental institutions are also excluded.

[2] See *Part Three: Implementing New Directions, Healthy Aging: New Directions of Care,* 1999: *page 66-69* for background. These recommendations and their significance were largely missed at the time as the media and public were focused on the public debate related to contracting out surgical services in the lead up to Bill 11.

[3] See *A Framework of Reform, Report of the Premier's Advisory Council on Health,* December 2001.

[4] With shorter hospital stays, refurbished long term care beds in some Regions are being used to replace acute care beds. New purposes include short-term palliative care, rehabilitation, transition, respite and sub-acute care (sometimes referred to as step-down units). Note that 3 and 4 bed rooms in traditional facilities are also being converted to 1 and 2 bed rooms. The Chinook Region's 10-year strategic plan for continuing care calls for an 80% reduction in traditional long term care beds between 2002 and 2012 to be replaced by 40% DAL units and 40% "enhanced" lodge units. Also see information on the Alberta Rural Affordable Supportive Living Program at http://www.seniors.gov.ab.ca/RASLP/

common language, as well as widespread differences among the nine (previously seventeen) regional health authorities responsible for implementing continuing care reforms, have led to a situation where little is known or understood about this new model of financing and delivery. Even less is known about the implications for residents in these settings and their families, both positive and negative.

The only readily visible change in many communities where traditional long-term care facilities have been substituted with Designated Assisted Living housing is a new modern building with private rooms replacing an old institutional-style building with three and four bed wards.[5] These environmental changes are obvious, and appear to be highly valued. However, it is less clear what scope of health care services and supports are provided in these new care housing complexes, who is responsible for arranging and providing required services, or exactly what expenses residents and their families face.

In the fall of 2004, it was announced that a recently built care facility in one Alberta community - Hinton, Alberta - was to be converted from "nursing home" to "designated assisted living" status. All residents would remain in place. This provided a unique opportunity for a small case study to explore the nature of this new model of delivery and financing, how it differs from traditional models, and how these changes affect the residents and their families when they transition from one model to the other. With the assistance of local community members and families of residents, changes in the nature, scope, sources, responsibilities and costs of services following the conversion in early 2005 were identified, documented and explored.

Local Context and Background

Nestled in the foothills of the Rocky Mountains just three hours west of Edmonton, Hinton is a town with about 10,000 permanent residents. It falls in the Aspen Health Region, one of nine health authorities in Alberta responsible for the allocation of health care resources to prescribed geographic populations. The town has a stable population with an average individual income of $23,000 and average family income of $57,000. Major industries are coal mining and a pulp mill. It also has a 17 bed public hospital, a 30-bed/unit public lodge, an ambulance service and a local Community Care/Health Unit office.[6]

For many years, members of the community lobbied public health officials to build a public long-term care facility in the town in order to keep friends and relatives close to home when the need for such care arose, often near the end of life. In 2002, the long awaited facility - attached by a corridor to the local hospital - opened its doors.

[5] Note: Studies in the field of gerontology in the 1970s and 1980s demonstrated the importance and value of a private living space (and privacy) to the quality of life for most long term care residents. As a consequence, replacing 3 and 4 bed wards has been part of the long-range plan for continuing care in Alberta since the early 1990s.

[6] The Alberta Seniors Public Lodge Program has existed since 1959. Run by local non-profit management bodies made up of community members and funded by municipalities, the provincial government and resident rents, these lodges were created to provide subsidized supportive housing (private room, meals, cleaning, laundry, social activities and 24 hour monitoring for safety and security) for *functionally independent* seniors with low and moderate incomes. The management body controls entry. The Community Care/Health Unit office is run by the Aspen Health Authority and responsible for community-based services, including home care assessment/coordination. Public home care services are available to lodge residents.

This new facility (built with a combination of public and private dollars and owned and operated by an experienced faith-based care organization) consisted of 20 "nursing home" beds and 5 secure "dementia cottage" beds. In keeping with the popular "campus" concept of providing independent and supportive seniors housing on the same building site as long term care facilities, the complex also had 27 independent housing units on the second floor. These studio and one-bedroom units (which all included kitchenettes) offered optional meals, housekeeping and laundry for additional fees. While the Aspen Health Region controlled access/entry to the nursing home and dementia beds, the supportive housing units were private rental units. Low occupancy rates for these units continued long after the facility opened, leading to losses for the operator.

In 2004, a decision was made by the operator and Aspen Health Region to convert the entire facility into a 52 bed Designated Assisted Living setting (including 15 dementia beds). The Town Council, community members and families raised a number of questions and concerns related to this change and its potential impact on the price and quality of services, but were repeatedly reassured that changes would have little or no impact – or improve the quality of care.[7] The conversion went ahead on Feb. 1st, 2005 and the case study officially began a few months later.

Methodology

Lynda and Ron Jonson with *Seniors I Care* in Hinton were key partners in this project. A number of planning meetings were held in Edmonton. Methods and strategies for completing the case study were identified and a research framework outlined. Documents and correspondence related to the conversion were obtained, reviewed and analyzed. Community and family members were asked to provide feedback about the nature and effects of these changes including perceived positive, negative and neutral effects. These included responses to specific identified categories of services as well as those identified by community and family members. This was done with the caveat that personal information would only be reported in anonymous and aggregate form in order to protect the identities of respondents and residents in care. Local media was monitored. Three days were spent meeting with community members and families in Hinton. The existence, eligibility criteria and scope of coverage and financial supports provided by provincial programs were also investigated. Regular environmental scans for new policy documents were conducted.

While the study proved more challenging than originally anticipated due to the demands and stresses on informal caregivers inherent in supporting someone "in care", the process of change in the care centre, and (often) a family member's own failing health, it has provided important new information and insights. Due to limited access to information and time constraints, it should be noted that detailed exploration and comparisons of important quality characteristics of care and supportive housing models identified in the literature (e.g. discharge policies, resident/family rights, risk management, safety standards, financial protection and complaints resolution processes) were not included in this case study.[8]

[7] Local newspaper articles January to June 2005 (The Parklander).

[8] For an excellent analysis of some of the issues in a Canadian context, see Charmaine Spencer, *Assisted Living Consultation Response: Health and Safety*, British Columbia, 2003, www.canadianelderlaw.ca

2. Case Study Findings

Given the ongoing changes and lack of standardization, this "real world" case study must be viewed as a snapshot in time – current as of October 2005. Key findings related to the scope and sources of services following the conversion as well as responsibilities for costs and some of the implications for residents and families are identified below. Details are provided in a comparison chart that follows. As well as outlining some of the differences between traditional care facilities and designated assisted living settings, this chart provides important insights into the range of products and services required by anyone with a chronic medical condition (stroke, multiple sclerosis, dementia, cancer) regardless of who pays or provides these products and services. It also clearly demonstrates the current phenomenon of "unbundling" and de-regulation of prices and controls in the health care system - similar to the unbundling and de-regulation of telephone and utility services (and many other services – both public and private) during the1990s.

Key Findings

Access controlled by regional health authorities and choices limited by ability to pay

Access to Designated Assisted Living beds/units is controlled in the same fashion as access to traditional long-term care facilities. Long-term care facilities in Alberta are considered to be "approved" nursing homes and auxiliary hospitals. Although governed by separate pieces of legislation, these two former distinct types of facilities were essentially merged under the same funding model in the early 1990s and the bar for admission raised. In general, entry to DAL units is restricted to those individuals who would otherwise be admitted to traditional long-term care facilities. According to the most recent information, the term *Designated*, used in conjunction with either *Assisted Living*, *Supportive Li*ving or *Supportive Ho*using, refers to spaces within buildings "that are *reserved* by a regional health authority and housing operators for persons who are assessed as requiring a high level of personal care and support services."[9] If the term *Designated* is not attached, these same settings or units can usually be accessed privately.

Eligibility for entry to DAL units is based on a health authority's assessment of someone's "unmet health needs" in his or her current living situation. (One example of an unmet health need would be if someone was unable to use the toilet without assistance and no one was available or able to assist him or her.) Once a decision for "placement" has been agreed to by all parties, the health authority contracts with the housing operator to provide the resident with a specified amount of around-the-clock access to "personal care" (i.e. hands-on nursing care such as assistance with bathing, grooming, toileting, transferring to wheelchair, incontinence care, medication assistance and oversight primarily provided by personal care aides) and assistance accessing other goods and services.[10] However, the scope of contracted services and staffing mix varies among sites and as does the price of rent and other support services. Unlike nursing homes and auxiliary hospitals, the province does not regulate rental fees charged residents or the scope and quality of services provided. Placement decisions are influenced by the ability and

[9] See Supportive Living Framework Working Group, *Alberta Seniors Supportive Living Framework,* June 13th, 2005. Document created to assist an MLA Task Force which appears to be based on earlier models developed by the Alberta Seniors Citizens Housing Association (ASCHA), a trade and lobby association for public (lodge) and private care housing operators, http://www.continuingcare.gov.ab.ca/pdf/Supportive_Living_Framework.pdf

[10] Many of these complexes offer similar units and services for fully private-pay clients.

willingness of an eligible candidate and their family to pay the basic rent and all the associated expenses and/or the availability of individually assessed government income subsidies.[11]

Far less included in the package of goods and services in DAL

Designated Assisted Living settings are considered homes, so those managing a medical condition and related functional disabilities (i.e. residents or their families) are responsible for paying all the defined "costs of living" in Designated Assisted Living settings, much as they would if they were living in their own homes.[12] Housing and "hospitality" services such as meals, laundry, cleaning and "life enrichment" for residents are considered private contract arrangements between the operator and a resident and/or their family/guardian. While basic monthly "accommodation" fees (rent and hospitality supports) in the case study decreased following the conversion to DAL, *far less* was included in the package of prepaid goods and services, particularly medically necessary supplies, supports and services. Regional health authorities are responsible for funding such supplies in traditional long term care facilities. [13]

Costs of medically necessary products and services shifted to residents and families

Following the conversion, residents and their families thus became responsible for the costs of a wide array of medically necessary products and services - subject to the availability of external provincial extended benefit programs, income subsidies and private insurance plans to cover all or part of these expenses. Since public extended benefit plans to cover these products and services outside hospital walls in Alberta, as in most Canadian provinces, are far more limited than most people realize, the greater the need for products and services related to someone's degree of disability or changing medical status, the greater the expense through co-payments, user fees, and retail purchases of goods and services. One consequence is that individuals tend to have less buying power than organizations (or the province); therefore, as well as shifting costs, there is a tendency for the cost of each item to be higher. In addition "shopping" opportunities and bargain hunting are often limited for persons with multiple functional disabilities who are usually unable to get out and about on their own and have few discretionary dollars for transportation.

Expenses less predictable and controllable with higher costs for those with greater care needs

Monthly expenses for residents and their families accordingly became far more variable and unpredictable – and less controllable - following the conversion. Most supplies are ordered by the care housing staff, but families are responsible for payment. Changes in prescribed medications, the loss of mobility or urinary or bowel continence, rashes and the need for oxygen or catheters and diabetic supplies all influence monthly expenses. So do changes in the *multiple* external programs, benefit plans and providers upon which residents now depend – including the Alberta

[11] For more background on the early development of DAL in Alberta see Wendy Armstrong, *Eldercare on the Auction Block*, Consumers' Association of Canada (Alberta), 2002. http://albertaconsumers.org

[12] Note: The costs of living are often higher for individuals with disabilities and medical conditions because of additional laundry costs, cleaning and sanitizing needs, special transportation and food, etc.

[13] However, the province appears to be moving to harmonize the funding model for long-term care facilities and DAL. Daily "accommodation fees" in traditional long-term care facilities have been redefined through internal policy interpretations and directives. (AH & W correspondence, 2002) Instead of being considered a "user fee" for the entire basket of products and services provided in such settings, the "accommodation" fee is now considered a separate envelope of loosely defined housing and support services paid by residents. This is separate from the envelope of funding provided to long term care facility operators by regional health authorities for direct "care" expenses. Resident fees in traditional long term care facilities increased significantly in 2003 to reflect these changes. For information and background on changing fees and other identified community concerns see www.continuingcarewatch.com.

Seniors Drug Plan, Alberta Aids to Daily Living (AADL), Regional Home Care Programs, multiple income subsidy programs, private insurance plans and retailers. For example, because DAL is classed as "private rental housing" (not a long term care facility), low and modest income families lost the provincial long-term care facility income subsidy following the conversion. Both the extra costs and the unpredictability were problematic for a number of families.

New financial burdens leading to family breakdowns

Most provincial "special needs" funds and health benefits in the community are based on family income and circumstances, not just the resident's income. This can create significant hardship for a spouse attempting to maintain a home setting on a limited or fixed income as well as provide for someone in care. Both the stress and limited income appeared to taking a toll on the health and well being of some spouses and extended families. Divorce, a commonly recommended remedy by lawyers and accountants, is under consideration by some families.

Costs influenced by multiple external programs, benefit plans and retailers – and shift to demonstrated financial need as basis for public health benefits

External public programs and benefit plans are undergoing significant changes as well. This adds to the unpredictability and expense for residents with high service needs. The scope of covered products and services in many community benefit programs is decreasing and the criteria to qualify for benefits are changing. Provincial extended benefit programs in the community are moving from a model of universal coverage of products and services for certain populations based on "medical need" to income subsidies or eligibility based on "demonstrated financial need". These income subsidies can then be used to pay increasing user fees and purchase necessary products and services in the private sector, often at higher retail prices. For example, diabetic syringes and testing supplies are no longer covered through any provincial extended benefit programs based on medical need. Instead, individuals who can demonstrate financial hardship are eligible to apply for a small income subsidy to cover part of these expenses through a new Alberta Monitoring for Health Program.[14] Reductions in the scope of products and services covered by traditional community benefit plans such as the Seniors Drug Program and private insurance policies are likely to continue as more costs are shifted from regional health authority and care organizations' budgets to these plans.

New barriers to accessing public health benefits: confusion, complexity, uncertainty and discomfort with process

Despite increased reliance on external programs and benefit plans, residents and families are not always aware of available subsidies, rules are unclear, and applicants are often refused. Following the conversion to DAL, both in-house and off-site care coordinators became responsible for identifying needs and assisting individuals to obtain benefits (and did assist many families); however, there are only so many programs to access and care coordinators' time is limited. Reminiscent of the days before universal public pensions and medicare programs, some spouses indicated they would rather go without basic necessities than deal with the complex process of applying for uncertain benefits and/or their discomfort asking for help and having their lives and finances scrutinized. A number reported having applied or knowing someone who had applied and been turned down.

[14] For a revealing look at the average out-of-pocket costs for diabetic supplies across the Canada see *The Diabetes Report 2005* published by the Canadian Diabetes Association. http://www.diabetes.ca/section_advocacy/index.asp

Support and oversight responsibilities transferred to families and friends

Families also experienced new responsibilities and time commitments in the DAL environment. These included filling out applications, gathering records, reading and asking questions about contracts, making retail purchases, providing more health oversight (noticing and calling attention to problems) and arranging and managing payment of bills. Such responsibilities can be stressful and challenging for frail or working spouses, particularly those with transportation, mobility, time, health or financial constraints, as well as for families living miles away. Functional literacy related to cognitive and physical impairments or medications can also be a problem for both residents and spouses. These new tasks were perceived to be add-ons to already significant demands on families (before and after the conversion) related to providing emotional and social support for a loved one "in care" and the need to fill perceived gaps in actual hands-on care (e.g. daily feeding) due to limited staffing.[15] Lack of access to care information and related expenses was also a problem identified by some families, despite being expected to pay the bills.

Loss of on-site resources (staffing) influenced quality of care and quality of life for residents

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The loss of on-site professional services such as RN and physiotherapist services was perceived by a number of study participants to have a negative ripple effect on the quality of care and quality of life of residents. Licensed Practical Nurses (LPNs) replaced RNs on-site following the conversion and RN assessment and on-call services as well as physiotherapy became of the responsibility of off-site professionals working for the Region's Community Care Office. Responses to in-house requests for an urgent assessment of the rapidly changing medical condition of a resident are reportedly timely; however, the availability of these professionals for less urgent assessments is now dependent on their caseload in the community. For example, the frequency of physiotherapy services for some residents decreased, leading to some reports of reduced ability to mobilize and increased discomfort due to lack of mobility. The reduced familiarity and continuity of RN assessment due to changing off-site nurses was felt to sometimes lead to delays in timely identification of problems and effective treatment.[16] Families had also been advised prior to the conversion that this change in facility status would lead to more individualized and responsive services for residents. However, there were no reported or perceived differences (positive or negative) related to the responsiveness of the care organization and staff members. For example, the standard of care in nursing homes in Alberta, including the Hinton facility prior to conversion, is to offer a resident one tub bath or shower per week. A request by one family for a second bath was refused both before and after the conversion. A major complaint both before and after the conversion was "too few staff" with no perceived differences in timeliness or quality of care.

The following chart (see next page) provides additional insights.

[15] The issue of inadequate staffing in long term care settings has been a growing concern in Alberta leading to a May 2005 *Report on Seniors Care and Programs* by the Auditor-General and an MLA Task Force, see Auditor-General's report at http://www.oag.ab.ca/

[16] Note: Since the bar for entry to nursing homes was raised in the early 1990s, most residents in such settings have multiple medical conditions and medication regimes which often require intervention.

Comparison Chart of "Unbundled" Services and Responsibilities (Alberta Nursing Home beds versus Designated Assisted Living beds)

SERVICE	BEFORE (NURSING HOME)	AFTER (DAL) - current to Oct. 2005
Access (Entry)	Entry controlled by Region with operator right of refusal.	No change. Entry controlled by Region with operator right of refusal.
Basic Fee Note: the same unbundling and redefinition of health services is ongoing in traditional long term care centres	$1470 per month for private room.* Note: The facility was built with all private rooms. Includes 3 meals, snacks and housekeeping. *(Housekeeping includes infection control measures as required group setting.)* Accommodation fees regulated by the province. *$48.30/day for private room at 30.5 days. Increase from $32.60 per diem in 2003	$950 per month for private room/studio $1050 per month for studio/kitchenette $1150 for dementia care in secured unit $1250 for one bedroom Includes 3 meals, snacks and housekeeping. *(Housekeeping includes infection control measures as required group setting.)* Accommodation related fees not regulated. If only a higher priced bed/unit is available, eligible candidate must take the available unit or be transferred to another setting, leading to families having to pay extra to keep someone in the community.
Long Term Care Accommodation Subsidy (from Seniors Income Benefit Program)	Yes. Low-income residents are eligible for income subsidy but must apply. Depending on income/marital status – cash benefits go up to $8,775 year.	No. Residents are not eligible for the LTC accommodation subsidy from *Alberta Seniors [Income] Benefit Program* as DAL is classed as rental housing. Some families lost subsidies of up to $300/month.
Nurse Call Bell Telecare 24 hour emergency support	Supplied by Centre	Resident responsible for $26.26 per month for *mandatory* basic telephone service, the costs of a telephone or rental and a $35 installation fee. This is required to activate Telecare call bell system.
Laundry	Personal laundry $35 /month	Personal laundry $35 per month. Increase to $39 in January 2006. Both linens (including incontinent pads) and personal laundry are done in home-use type machines. This raised some concerns related to infection control.
Bed, furniture, bed linens, towels, etc.	Supplied by Centre	Residents responsible for providing bed and furniture plus bed linens and towels. Community agencies report calls from families and friends seeking suitable second-hand furniture due to limited funds.

Medical supplies and equipment (for long term use) Oxygen supplies, incontinent supplies, bed rails, catheters and bladder equipment, wound care and dressing supplies, colostomy supplies, braces, sheepskins, special cushions, wheelchairs, commodes, tube feeding supplies, pumps	Supplied by Centre	Resident responsible for up to $500 per year (via 25% co-payments) for eligible supplies obtained through *Alberta Aids to Daily Living (AADL) Program* as per the program criteria plus any additional extra billing by the vendor. Each item must be individually authorized based on assessed needs by qualified person. Low-income families can apply for a waiver of fees based on family income. Must pay full costs for non-covered supplies or when use is above slowed quota. (e.g. oxygen) To be eligible for AADL funding, a person must have a long-term disability lasting six months or more, or a chronic illness or terminal illness. Short-term supplies are not covered. Coordination and delivery remain the responsibility of the Centre.
Diabetic syringes and testing supplies **Tube feeding equipment and supplies**	Supplied by Centre Supplied by Centre	Resident responsible. AADL does not fund diabetic syringes, testing supplies or tube feeding equipment and fluids. Neither does the Alberta Seniors Drug Benefit Program. Eligible low-income residents can apply for an income subsidy from *Alberta Monitoring for Health Program* to cover part of the costs of diabetic supplies - based on a case-by-case review. Tube feeding equipment and supplies are covered by a separate provincial Home Nutrition Program run by the Capital Health Authority, however, patient co-pays are $106 per month unless eligible for a subsidy under some other income support program.
Short Term Dressing and other Medical Supplies and Devices, etc.	Supplied by Centre On-site stock.	Short-term wound dressings are brought in by Home Care nurses and left in individual resident's room. Staff reportedly run out of supplies as need is difficult to anticipate. Responsibility for payment of short-term medical supplies will depend on the existence of external public or private benefit plans and each *Region's Home Care Program* policies.
Personal Care Supplies e.g. special peri-wash to avoid skin-breakdown with incontinent patients.	Special care supplies such as medicated creams and peri-wash for incontinent residents supplied/stocked by Centre. Personal supplies such as shampoo, soap, comb, toothbrush, etc. responsibility of resident.	Responsibility of resident. Special supplies must be ordered on individual basis and/or purchased by families or friends in *retail stores* or ordered by care-housing staff. Prices vary widely. For example, peri-wash ranges from $6 to $11 at different stores in Hinton. Notes are left at the bedside to alert families of resident needs or ordered by staff. Some families cannot

		readily afford these items.
Medications Prescriptions Non-prescription medications such as enemas, suppositories, Tylenol, etc.	Supplied by Centre	Most residents are responsible for costs, but most residents covered by current premium free *Alberta Seniors Drug Plan*, but must pay 30% of prescription costs up to maximum of $25 per prescription for covered drugs. Non-seniors (e.g. individuals with multiple sclerosis or other chronic debilitating diseases) must rely on out-of-pocket payment, private benefit plans or the government sponsored *Alberta Non-Group Blue Cross Plan* for those unable to obtain private drug coverage (requiring premium payments and co-payments). If recipient receives income from low-income *Assured Income for the Severely Handicapped (AISH)* program, drugs are covered. Some residents fall through the cracks. Prescription and non-prescription drugs are now packaged and delivered by retail drug store of choice and drugs are required to be packaged in a special way by the Centre so they can be given by care aides – a task called "medication assistance". The special packaging (and/or frequent prescription changes) can triple patient costs because prescriptions are only filled for one month at a time (rather than normal 3 months in community settings) because of the need for special packaging and frequent prescription changes with such clientele. NOTE: It is not unusual for residents to be on a number of medications - both on a continuous and intermittent basis as health problems arise. Personal costs for prescription drugs for one person (senior) ran $121, $115, $144 and $190 over a 4-month period for a *middle-of-the-road* basket of medications. The need for occasional medicine like Tylenol and enemas must be anticipated and stocked in advance, however costs to residents often limit the amount ordered. Coordination and delivery of medications remain the responsibility of the Centre.

Dental, vision care and eyeglasses Note: dentures and eyeglasses often tend to "wander" or be damaged in care settings – leading to a more frequent need to replace	Responsibility of Resident As of 2005, low and modest income seniors are eligible to apply for special funding. .	Responsibility of Resident Seniors with low to moderate-income seniors are eligible to apply for special funding from *Dental Assistance Seniors Program* or *Optical Assistance Seniors Program* based on family income. Prior to April 2002, all seniors were provided with limited dental and vision benefits through a public benefit program administered by Alberta Blue Cross - although benefits had been reduced from previous 1993 levels. This program was discontinued April 1, 2002. In 2005, the province introduced a new program for some limited coverage based on demonstrated financial need.
Professional Services Registered Nurse Physiotherapist	Provided by Centre on site. One R.N. on site 24/7 responsible for assessment, treatment, care planning and health monitoring. One physiotherapist and one Rehabilitation assistant on site.	RN and rehabilitation services provided by Aspen Health Region's *Community Care Office*. Responsibilities for RN Case Management services M-F (described as assessment and treatment, case coordination, care planning and health monitoring) transferred off-site to *Community Nurses*. Rehab assistant only on-site. Professional physiotherapy assessments transferred to staff with regional community care office. Less regular mobilization or treatment reported, particular for residents requiring two-person assistance. In-house manager on site M-F.
After Hours RN Care (Evenings and Weekends)	Provided by Centre on site.	24-hour access to RN on-call services (primarily assessment) is provided by the Health Region's *Community Care Office***.**
Staffing and 24 hour oversight.	Registered Nurses and Nursing Attendants provide care. 1 RN on each shift. Families report shortfalls in staffing.	Licensed Practical Nurses (LPN) and Nursing Attendants provide care: 1 LPN on each shift. Loss of in-house RN assessment of wounds or condition over time identified as problem. Families report shortfalls in staffing. Note: No formal training is required in Alberta for nursing aides who are called "personal care attendants" but most have some formal or in-house training.

Recreation	A recreation aide provides planning and programming.	No change. However, designated recreation space removed due to renovations to accommodate changes.
Physician Services	Residents cared for by their own physician at the facility. Medical Director required.	Residents still cared for by own physician, but no Medical Director is required. Standards related to LTC facilities no longer apply. In some other DAL settings, residents or family are responsible for transportation to the doctor's office if the doctor unwilling to make house calls. The author was unable to obtain information re: differences in allowable physician billings to the Alberta Medical Plan between settings. (The fee schedule differs for long term care facility visits and home visits)
Medically required Transportation Ambulance service and transportation to medically required treatments outside facility.	Supplied by Care Centre.	Resident responsibility. Payment of medical related transportation for assessments or treatments as well and any required companion and ambulance service is now the responsibility of residents. In some circumstances, the Regional Health Authority or *Alberta Blue Cross for Seniors* will pay all or part of the costs of ambulance services. (You'll find out if/when you get the bill.) Residents are responsible for co-payments. Those who do not qualify for benefits must insure privately or pay the full costs. A privately arranged return trip to Edmonton (for transportation to a specialist in a special vehicle) was quoted at $3,000. Centre arranges transportation.
Food Services Convenience/ Quality	Prepared on site. Snacks left out and available to residents in common room. Meals provided by tray service in rooms as required.	Uncertain at this time. Notice of intention to contract out food services led to resignation of food preparation staff. Food is currently being provided by local hospital (connected by corridor). Shortly after the conversion, formerly accessible fridge was locked and snacks no longer left out – but changed after families complained. No food on site at present to meet needs of sick residents unable to take regular meals. There is an additional $30 month charge for regular tray service to room.

These key findings and chart reveal significant hidden human and financial costs arising from this new model of delivery and financing continuing care services, many which are beyond the everyday view of the public, policy makers and even the care organizations involved.

3. Discussion

Soon after release of the "Broda Report" in 1999, the Government of Alberta set strategic directions to guide implementation of the Committee's recommendations for "continuing care reform". The stated purpose of these reforms was "to develop an improved, sustainable and affordable continuing care system" and provide "accessible, affordable and high quality continuing care services." [17] It was further anticipated these reforms "would ensure that as Albertans age, they:

- Are treated with respect and dignity
- Have access to information that allows them to make responsible choices regarding their health and well-being: and
- Can achieve quality living, supported by relatives, friends and community networks and by responsive services and settings."

The expansion of "Supportive Living as an alternative to Long Term Care Centres" was a key strategy undertaken as part of these reforms, particularly the implementation of Designated Assisted Living programs in new supportive housing complexes built in partnership with both for-profit and not-for-profit housing developers.[18] These Supportive Living programs, including Designated Assisted Living are often promoted as a new and more responsive approach to meeting the care needs of traditional long term care clients, enabling recipients of care to effectively "age in place". However, the most prominent features in this case study were:

- Increased fragmentation;
- De-regulation of price and quality controls;
- Unexpected and unpredictable costs, stresses and burdens on residents, elderly spouses and extended families, including greater need to understand and navigate complex systems of care; and
- A shift in provincial policies from a "health needs" based entitlement for public health care benefits to a welfare subsidy model based on demonstrated "financial need" and income/means testing of residents and/or families.

It is difficult to reconcile these findings with the Alberta government's stated goals and objectives for continuing care reform. This model appears to be driving *up* the expense and *decreasing* the accessibility and affordability (i.e. choice) of health-related products, services and settings. Families in this study, most in their senior years, did not reflect a feeling of being treated with respect and dignity related to their identified needs or feel they had information and opportunities to make healthy choices and achieve quality living, Although participants did reflect a feeling of

[17] See Alberta Health and Wellness, *Tracking Progress: A Progress Report on continuing care Reform in Alberta,* 2002.

[18] See Government of Alberta Press Releases, *Supportive living facilities for seniors to be built in rural Alberta,* October 21, 2004 and *Provincial surplus helps create more housing in rural Alberta; Projects will support seniors, people with high health needs, and lower income Albertans,* November 17th, 2005

being supported by family and friends (and many of the staff members in the facility), they did not feel the organizations and process served them well.

Four significant observations can be made.

- First, this financing and delivery model makes the assumption that the products and services provided in this setting are being provided for relatively healthy people and these products and services (and settings) are largely discretionary in nature or simply a matter of convenience. However, the criteria for entry to DAL settings (i.e. significant unmet health needs) would seem to contradict this.[19]

- Second, by removing services to resemble the relative lack of resources available to those managing chronic conditions at home, rather than increasing the care available to those in the community, this model appears to be going in the reverse direction of recommendations in the international literature. In particular, the ensuing fragmentation does not jibe with the importance the literature has placed on having a high degree of integration between continuing care services in alternative settings and other parts of the health care system.

- Third, the additional responsibilities and financial hardships rarely fell on the residents themselves because of their limited capacity to take on these extra tasks and shortfalls, but had a profound effect on spouses and families.

- Fourth, the shift in public policy from a universal "health needs" based entitlement for traditional health care benefits in the community to a welfare-model of income/means testing has far reaching ramifications for families, employers and communities.

1. Confusion about who this model is designed to serve

During the course of this study, a member of the Hinton community received a letter from the local government MLA in response to concerns expressed about the conversion of the local facility to DAL status. The letter sought to reassure the community member stating, "Designated Assisted Living is a housing option which promotes independence for capable seniors and increases choices in living arrangements."[20]

The residents in this case study, however, could not be described as capable, independent and relatively healthy seniors. Many appeared to be at the high end of the A to G classification system used in Alberta to assess continuing care clients (i.e. nursing home and auxiliary hospital residents) with G indicating the highest care needs. Some could not effectively communicate. Others were wheelchair-bound, medically fragile and dependent on staff for bathing, grooming, dressing, toileting, taking medication, incontinence care, wound dressings, tube feedings assistance eating, managing their fears and memory loss, monitoring flare-ups of medical conditions and participating in activities. Some were in dementia units.

[19] It should be noted a public lodge facility (i.e. Pine Valley Lodge under the Evergreens Foundation) in town provides supportive housing services (bed-sitting room, laundry, housekeeping, meals, social activities and 24 hour monitoring for safety) for frail but otherwise independent seniors based on social needs.

[20] Provided by Lynda Jonson, 2005.

It is difficult to imagine how these individuals could be considered capable of making complex financial decisions, analyzing contracts or shopping for alternative arrangements if they did not find services to their liking. Furthermore, someone cannot choose a DAL setting without approval of a health authority based on a formal assessment of unmet health needs and adequate funds to manage all the bills.

The problem is that a system for the financing and delivery of services for relatively healthy people with limited needs and a genuine alternatives is rarely appropriate, effective or responsive for not-so-healthy individuals with multiple functional limitations, a high degree of dependency on care providers and no real alternatives. The original user-pay assisted living models in the United States were designed for individuals with far fewer (and more intermittent) care needs. Even then, most assisted living settings are unaffordable to large segments of the population.[21]

2. The high costs of fragmentation

The transaction costs (and time) associated with multiple evaluations and income subsidy programs in this model appear to be significant. There are also costs associated with line-by-line accounting and billing unbundled goods and services on an individual basis. Packaging, distributing and funding medications and medication assistance in the manner identified in this case study may reduce the direct costs to the care organization, but it increases the costs to both the Seniors Drug Benefit Plan and residents and their families – and increases the overall costs within the system, including supplier costs. The loss of such economies of scale (particularly when all residents have such high care needs) appears to have contributed to higher prices and higher total costs, thus reducing access, affordability and sustainability. The remarkable fragmentation (and complexity) of funding sources and responsibilities also appeared to result in less continuity and timeliness in meeting residents' needs and less accountability.

Literature in the field of alternatives for care of the frail elderly and disabled suggests the key to providing effective and affordable programs and living arrangements is integration and coordination.[22] In particular, accurate assessment of an individual's need for specific types of care (which may change frequently), sufficient funding, and appropriate targeting of services so that people get the services they need are critical. Particularly good results can occur when care for the frailest subset of seniors is well coordinated, and focused on preventing their chronic conditions from flaring up and requiring hospitalization and specialist care. One of the most effective strategies appears to be comprehensive service packages funded through an integrated budget so that all the various bits and pieces of care required are funded from the same envelope. Carol Kushner has closely monitored and written about continuing care in Canada and around the world. She has observed that the "mission" of a care organization can also make a difference:

> *"Quality of care for vulnerable groups, like the frail elderly, seems best protected when such services are delivered by mission-driven organizations --agencies that are absolutely dedicated to offering superb geriatric care. Beyond that, getting the incentives right is critical in order to avoid exploitation. You want to avoid situations*

[21] See Phil Gaudet, *The Shift from Nursing Home to Assisted Living: Is it defensible?,* Stride Magazine, 2002, http://www.stridemagazine.com/articles/2002/q2/assisted.living/

[22] See information, working papers, publications and links on M-THAC web-site http://www2.m-thac.org/cgi-bin/WebObjects/mthac.woa and the associated Canadian Research Network for Care in the Community (CRNCC) at http://www.hpme.utoronto.ca/English/page-1-797-1.html

> *where service organizations can profit by selling add-on products and services that are not strictly necessary because doing so could speed the decline in a senior's ability to function independently. At the same time, you need to make sure that the envelope of funding is sufficient to respond appropriately to needs. The bottom line is you don't ever want to stint on necessary care."*[23]

Instead of funding care-related services within one envelope, this case study reflects increasing unbundling and fragmentation of financing and delivery of services. Some earlier Alberta models of DAL appear to have included more products and services – such as drugs, recreational therapists and registered nurses - provided by the care organization. Other products and services not included in the "package" were also far more readily available through extended public health care benefit programs that have since undergone significant changes.

Now, it appears as though the public benefits available to individuals with substantial care needs in special care settings are the same limited benefits available to individuals with lesser needs living independently in the community. This was affirmed by a recent RFP (request for proposals) by the provincial government looking at the feasibility of replacing current public health care funding models with risk-rated insurance models. In the proposal, community-based continuing care services are described as "home care" services provided to individuals in their own homes and supportive living environments. As noted in the introduction, public funding for products and services required in home care situations is extremely limited at present.[24]

Finally, this fragmented model makes it impossible for anyone (policy makers, the public, families or residents) to really "know" or effectively manage the prices and costs associated with the need for ongoing care supports – be it due to a stroke, dementia, multiple sclerosis, an accident, arthritis, cancer or multiple disease conditions. The costs of gathering and collating information in a meaningful way from so many different funding and delivery sources would be significant, and it is highly doubtful that researchers would be able to tease out and capture the important transaction costs that are embedded in so many discrete functions and activities. Private spending is also largely invisible and varies by individual and by month. Public funding agencies rarely track it. Indirect costs to families are discounted. Given the challenges encountered in this study and the increased reliance on private spending, is capturing this information on a regular basis even possible? How can citizens or policy makers make good decisions without it?

3. The capacity of families

The shift to this new model of financing and providing care appears to be significantly increasing the burden on family members, often with limited capacity themselves. In fact, families are expected to take over many of the functions and responsibilities of case management and coordination. These new responsibilities and hardships rarely fall on the residents themselves because of their limited capacity to take on these extra tasks or short falls in financing. Instead, these burdens affect the quality of life and health of family caregivers with both legal and moral

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[23] Interview and correspondence with Carol Kushner, also see Carol Kushner, *No place like home: A discussion paper on long-term care*, Health Connections 99, May 1999, and Carol Kushner and Michael Rachlis, *Home Free: Prospects for the frail elderly in a national home care program*, Conference Proceedings and analysis, Health Transitions Fund, Health Canada, January 1999.

[24] See Alberta Health and Wellness RFP Number 05-190, *Health Benefit Design Options*, 30/09/05, http://www.health.gov.ab.ca/Key/reform/RFPHealthBenefitDesign.pdf

responsibilities to a loved one in care. Many of family members (spouses, sons, daughters, friends, parents) have already been stretched thin providing care at home for months or years prior admission to a care housing setting, and often only seek out such settings because the capacity of the family has been exceeded, often through the death of a care-giving spouse. Most families did not feel they had a "choice" related to their degree of involvement.

While the original Assisted Living "philosophy" of a more home-like setting, managed risk under the watchful eye of a dedicated and licensed care organization and a three-way partnership (among a care organization, the resident and family) is a refreshing change from more rigid medicalized settings, expecting too much of families or friends can have negative consequences for the well being of residents. Research over the past decade by Janet Fast and Norah Keating at the University of Alberta has found that the most important contribution of informal family caregivers is the emotional and social support they provide to recipients of care, and that burdening families with too many care tasks limits their capacity to provide such support.[25] Even the otherwise positive evaluation of the first Assisted Living pilot of the Good Samaritan Society in Alberta found that as residents "aged in place" (or more precisely, deteriorated due to a medical condition) and workloads increased staff tended to lose their client-centered focus and families carried increasing responsibilities for both hands-on care and other tasks.[26]

According to their ongoing research, these extra responsibilities also have a large ripple effect - on the children and spouses of informal family caregivers, the employers of family caregivers and society at large. Such ripple effects include strained family ties due to forfeited income (and forgone pensions) of informal family caregivers, deterioration of marital relationships and deterioration of the health of family caregivers. Employers bear additional costs when family caregivers come in late, leave early, drop back to part-time, choose early retirement or give up work entirely. Society bears extra costs through lost tax revenues, higher poverty rates, family bankruptcies and new demands on the health system.

4. Moving from a 'Medicare' to a 'Medicaid' model of funding health care

Since release of the Broda report in 1999, much of focus of media and public attention in Alberta has been on the nature of suppliers "delivering" services paid with public dollars and how these services should be organized. Somehow, the public and media appear to have completely missed the changes on the "payment" side of health care as the site of care has shifted outside institutional settings. Political columnists frequently bemoan that the Alberta government has not moved forward on long-promised and/or long-threatened reforms to the health care system. Yet, simply by recasting health care facilities as "housing" and health care benefits as "income subsidies" within a larger context of continuing care reform, a remarkable range of medically necessary health care goods and services have been unbundled, de-regulated and de-listed. To use the nomenclature of the key US public programs for health insurance; one might say that the model of funding for a broad sweep of health-care products and services in Alberta has shifted from a Medicare-like (needs-based) model to a Medicaid-like (income-based) model. [27]

[25] Personal Interview with Dr. Janet Fast, 2005 plus RAPP http://www.hecol.ualberta.ca/RAPP

[26] See *Evaluating Programs of Innovative Continuing care* (EPICC) series, U of A, Department of Ecology, March 1998, http://www.hecol.ualberta.ca/RAPP

[27] In Canada, Medicare generally refers to public insurance for physician and hospital care, although it is often used to describe any public funded health benefit program. In the US, Medicare is the national program which covers everyone over the age of 65, plus certain specified disability groups, allocating services on the basis of needs, regardless of income or ability to pay. In contrast, Medicaid is a series of federal-state partnerships, run at the state level, which

It now appears as though acute care hospital and doctor services may be going down the same route. Descriptions of the Alberta Premier's "third way" initiatives posted on the Ministry of Health and Wellness web site in the summer of 2005 bear a remarkable similarity to statements and recommendations in the 1999 Broda Report. The following statements were posted on the Health and Wellness web site in July 2005 related to intended reforms for acute care services.

- "Albertans will soon have a much wider variety of health care options to choose from."
- "No Albertan will be denied basic health services because they cannot afford it."

Most Albertans assume these statements mean that everyone will continue be eligible for public funding of current insured hospital and physician services based on medical need. Instead, based on last five years experience with "continuing care reform", these statements could also mean that hospital and physician acute care services will be unbundled and basic services redefined and reclassified. [28] Albertans requiring these services may ultimately be expected and *obligated* to pay for unbundled products and services unless they qualify for public subsidies based on demonstrated financial need. Orders in Council passed by the Alberta Cabinet in July 2005 have already set the stage for such unbundling and discretionary charges to occur.[29]

Final comments

This case study of changes in the funding and delivery of continuing care services through the conversion of one Alberta Nursing Home to a Designated Assisting Living program has provided important insights into the shift to home and community care. On the surface, Designated Assisted Living appears to be a positive response to pleas from the disabled elderly for less depersonalizing "institutional" care and more opportunities for privacy and control in their own home or home-like settings. The original philosophical concept behind assisted living appears sound. After all, allowing individuals with complex care needs to have more of a say in how they live their lives and take measured and managed risks under the watchful eye of committed care organization has obvious appeal. Encouraging individuals to help themselves and maintain a more normal life – with just the right amount of help when they need it – assists them to maintain their capacity and function, reduces the need for staffing and lowers human and financial costs for everyone involved. [30] However, it also seems clear that "the devil is in the details" when it comes to both quality and cost. The current push in Alberta to develop new and more aesthetically appealing building stock to replace older run down institutions holds a great deal of merit. However, this case study (which removes the variable of building design) demonstrates just how important it is to find *right* funding and delivery model in order to ensure access, safety, quality and affordability for both recipients of care and their families.

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gives limited coverage only to those falling below a certain income threshold; the 'working poor' is likely to be ineligible and hence not to be insured at all.

[28] See revised and updated Alberta Health and Wellness document, *Getting on With Better Health*, dated August 10th, http://www.health.gov.ab.ca/Key/reform/AHW_WebFinal_REV.pdf

[29] See Orders in Council at http://www.gov.ab.ca/home/Orders_in_Council/2005/705/2005_343.html and http://www.gov.ab.ca/home/Orders_in_Council/2005/705/2005_344.html

[30] Jeremiah Tate and Andrew Butler, *What a Difference a Year Makes: Assisted Living – Opportunities and Risks*, June 2002. (In response to the B.C. government's announced plans to adopt the "Alberta model" for continuing care.)

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