The Best of Care: Getting It Right for Seniors in British Columbia (Part 1)



Public Report No. 46, December 2009 to the Legislative Assembly of British Columbia

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Library and Archives Canada Cataloguing in Publication

British Columbia. Office of the Ombudsperson

The best of care: getting it right for seniors in British Columbia (Part 1). Public report no. 46 to the Legislative Assembly of British Columbia

Includes bibliographical references.

Available also on the Internet.

ISBN 978-0-7726-6184-5

Older people — Services for — British Columbia — Evaluation.
 Older people — Care — British Columbia — Evaluation.
 Older people — Government

policy — British Columbia. I. Title. II. Series.

HV9277.B74 2004 362.609711 C2009-904301-7

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Table of Contents

From the Ombudsperson	
Background	11
Origins of Investigation	11
Actions to Date	12
Responsibility for the Care of Seniors in British Columbia	13
Goals and Values	14
Residential Care in British Columbia	15
Community Care and Assisted Living Act	17
Section 12 of the CCALA	18
Residential Care Regulation	19
Hospital Act	20
Investigation	
Commitment to Care and Residents' Rights	
What We Heard	21
Unclear Understandings of Care Expectations	
Models in Other Jurisdictions	25
The Situation in British Columbia	28
At the Beginning of Our Investigation	
The Current Situation	
Finding and Recommendations	30
Public Information and Reporting	31
The Current Situation	31
Information About Residential Care Provided by the	
Provincial Government	31
Community Care Inspection Reports	33
February 2009 Home and Community Care Directive	34
What We Heard	35
Lack of Information About Facilities	36
Models in Other Jurisdictions	38
Conclusion	
Finding and Recommendations	41

Table of Contents

Resi	dent and Family Councils
	The Current Situation
	Regulations that Affect Resident and Family Councils
	Resident and Family Councils Across the Province
	What We Heard
	Models in Other Jurisdictions
	The Benefits of Resident and Family Councils
	Conclusion
	Finding and Recommendations
Sum	mary of Findings and Recommendations51
App	endices
A.	Response of the Ministry of Health Services and the Ministry of Healthy
	Living and Sport
В.	Excerpt from the Health Statutes (Residents' Bill of Rights) Amendment Act 60

From the Ombudsperson



This report is the first of two from the Office of the Ombudsperson on seniors' care in British Columbia. In this report we have focussed on the most frail and vulnerable seniors – those who need 24-hour care provided in residential care facilities.

Early in our investigation, we identified three interrelated areas where we believed straightforward changes could quickly improve the quality of life for these seniors. The changes we recommended were: clearly setting out the rights of seniors living in all types of residential care facilities and ensuring these rights were respected; providing timely access to useful, consistent and comparable information on residential care

facilities; and clarifying and providing support for the role of resident and family councils.

While I am satisfied that some of our recommendations, such as the residents' bill of rights, have been accepted and are already being implemented, I remain concerned this is not the case with other recommendations, even when the ministries have indicated they accept the purpose and intent of the recommendations. It is disappointing, for example, that our recommendation to create a single, provincial website that would provide timely access to useful, comparable information about residential care facilities has not resulted in a commitment to achieve that goal.

I hope that the significant public interest in this area will encourage full and timely implementation of all our recommendations.

Our second report in the area of seniors' care will deal with a broader range of care options, including home support, assisted living and residential care, and will examine issues such as access, standards, and monitoring and enforcement.

Kim S. Carter Ombudsperson

Province of British Columbia

Kim S. Carter

Executive Summary

In 2008, while visiting different regions of the province, I heard increasing public concern about a number of issues relating to the care of seniors in British Columbia. On August 21, 2008, I initiated a provincewide investigation to look at seniors' care, with a specific focus on issues of access to information, access to services, quality of care, standards of care, monitoring and enforcement, and complaints processes.

The public response to this investigation has been unparalleled in the history of our office. We received more than 600 responses to the questionnaire posted on our website, spoke with more than 300 people by phone, and opened more than 200 individual complaint files. Complaints have covered issues from lack of information, to delays in access to services and from poor food quality to inadequate responses to concerns about care.

The investigation team visited 50 residential care and assisted living facilities across the province including facilities in each health authority; in rural, suburban and urban areas; and public, non-profit and privately operated facilities. We held meetings with the Minister of Health Services and ministry staff at the end of September 2008 and with the Minister of Healthy Living and Sport and ministry staff at the end of October 2008. In February 2009, we discussed some preliminary results (Part 1) of the investigation with the ministers and ministry staff and in March 2009 provided them with a copy of a draft of this Part 1 report, under section 17 of the *Ombudsperson Act*. Meetings were held with both ministries at the beginning of April 2009 to allow them to provide their initial responses for our consideration. We provided a final draft to the ministries in July 2009. The ministries submitted their joint and final response to us, which can be found in Appendix A, in late November 2009.

The ministries have accepted and are implementing four of the ten recommendations made in this report. In the case of the other six recommendations, while the ministries have stated that they accept the recommendation, or the intent of the recommendation, the actions they propose to take are, in my view, insufficient to address the problems identified. Consequently this is a public report under section 25 of the *Ombudsperson Act*.

Our investigation highlighted that residential care in British Columbia today can be provided in a variety of ways, and by a variety of agencies, organizations and entities. The applicable legislative and regulatory framework in British Columbia is complicated. Care may be provided in a community care facility that is licensed and regulated under the *Community Care and Assisted Living Act*. It may also be provided in an extended

¹ Facilities that provide residential care to three or more people must have a valid community care facility license, whether they are publicly or privately funded.

Executive Summary

care hospital or a private hospital, both of which are licensed and regulated under the *Hospital Act*. Facilities may be publicly owned and operated or operated by private non-profit or for-profit entities.

Subsidized residential care is funded in part by the regional health authority and in part by the individual senior. To receive subsidized care a senior must be assessed as unable to function independently because of chronic, health-related problems. The daily funding provided to residential care facilities by the regional health authorities generally ranges from \$95 to \$262 per resident per day. As of January 2010, the charge to individual residents will be between \$29 and \$95 per day, depending on their after-tax income. Facilities may also charge residents additional fees for some items and services.

Access to residential care facilities is governed by the provincial government's Access to Residential Care Policy, which is commonly referred to as the first available and appropriate bed policy. In practice, this policy means that seniors seeking a place in a residential care facility are expected to accept the first bed offered to them. When seniors are offered a place in a residential care facility, they must be prepared to move into the facility within 48 hours. Then they can ask to be put on a waiting list to be transferred, if the facility they moved to was not their first choice.

Seniors or their families who can afford to do so may also choose to pay the full cost of residential care services at private facilities.

Commitment to Care and Residents' Rights

In the course of our investigation, we heard from concerned seniors and their families who did not feel they had an adequate understanding of the level of care that seniors are entitled to receive in residential care facilities. People told us that they were reluctant to raise concerns about the level of care that facilities provide, in part because they were not confident about what residents were entitled to receive or what their rights were.

We raised some of the concerns that people had brought to our attention such as food quality, response times to call buttons, medication errors and assistance with personal needs with the Ministry of Health Services and the Ministry of Healthy Living and Sport. The ministries told us that if such concerns were raised with facility operators and regional health authorities, the ministries expected they would have been taken seriously. The ministries said these were the sort of concerns that should have been investigated promptly and if substantiated, should have resulted in timely and specific remedial action.

Executive Summary

They said that if these concerns were not appropriately dealt with by the facility or health authority, the ministries themselves wanted to hear about them, so that they could ensure appropriate action was taken.

It is difficult, however, for people to persevere with their concerns and complaints if they do not know what their rights are and what treatment they can reasonably expect from a residential care facility. It can be challenging to continue to press forward to obtain a timely response or adequate remedial action without a clear idea of what a person's rights are.

Both Saskatchewan and Manitoba have regulated the rights of seniors in residential facilities.² Ontario passed the *Long-Term Care Homes Act* in 2007, which is scheduled to come into force as soon as supporting regulations are complete.³ In the United States, the federal *Nursing Home Reform Act* (also known as the *Omnibus Budget Reconciliation Act of 1987* or *OBRA 87*) sets national minimum standards of care and establishes rights for people living in certified Medicaid and Medicare nursing homes.

While the different acts and regulations that govern the provision of residential care in British Columbia impose obligations on facility operators, we concluded that a clear understanding of what the government's commitment to care is — what residents' rights are — would assist not only residents and their families, but also health authority staff and facility staff. A clear statement of residents' rights should also reduce misunderstandings and miscommunications and facilitate consistency of expectations and service delivery.

I therefore recommended in Recommendation 1(a) that the ministries take the necessary steps to ensure a commitment to care and the rights of seniors living in all residential care facilities be set out clearly in law by March 31, 2010; that the commitment and the rights be posted at the entrance to facilities where they are easily visible to residents and visitors alike (Recommendation 1(b)); that the ministries develop a reliable and objective process to monitor and evaluate the degree to which residents' rights are respected (Recommendation 1(c)); and that the ministries publicly report the results of this monitoring and evaluation annually, commencing in 2011 (Recommendation 1(d)).

² Personal Care Homes Regulations, 1996, R.R.S., c. P-6.01 Reg. 2, ss. 34, 34.1, 35 (Personal Care Homes Act, S.S. 1989-90, c. P-6.01) Personal Care Homes Standards Regulation, Man. Reg. 30/2005, part II (Health Services Insurance Act, C.C.S.M. c. H35).

³ The Act received royal assent on June 4, 2007. At the time this report was being published, it had not yet come into force. The Ontario government is in the process of circulating draft regulations, which are to be completed before the Act comes into force.

Executive Summary

The ministries accepted the first and second recommendations and the implementation process has already resulted in the passage of Bill 17, *The Health Statutes (Residents' Bill of Rights) Amendment Act 2009* on November 2, 2009. The *Residents' Bill of Rights* requires facilities to post the rights in a prominent place in each facility. I consider this to be adequate and appropriate action in response to these recommendations.

The ministries have indicated that they accept the need for a reliable and objective process to monitor and evaluate the degree to which residents' rights are respected. They have explained that complaints about breaches can be dealt with by either regional medical health officers or the Patient Care Quality Offices, and that these complaints will be tracked and reported regularly to the Ministry of Health Services. The ministries would then rely on these bodies to raise any issues that they could not address themselves to the highest levels of the health authority or to the ministries.

In addition, the Ministry of Healthy Living and Sport will require community care licensing staff to monitor facility compliance with the *Residents' Bill of Rights* and report their findings to the ministry on a regular basis, by March 31, 2010.

While these are excellent first steps, I still consider these actions inadequate. This is because there is no commitment that the regular reports from the Patient Care Quality Offices to the Ministry of Health Services will include the number, types and outcomes of complaints related to the *Residents' Bill of Rights*. Also lacking is the ministries' commitment that licensing will play an equally active role in monitoring facilities regulated by the *Hospital Act* (approximately 110) as it does in monitoring facilities regulated by the *Community Care and Assisted Living Act* (approximately 380).

In addition, I would encourage the ministries to include annual resident and family surveys in their monitoring and evaluation processes and to work with family councils when doing so. This would be an important, respectful and inclusive step to ensure that the monitoring process takes into consideration the views of residents and their families.

While the ministries have indicated they accept Recommendation 1(d) to report publicly on their proposed monitoring and evaluation beginning in 2011, after determining a fiscally responsible approach to doing so, given that the ministries actions in regard to Recommendation 1(c) are not adequate, their proposed reporting suffers the same deficiency.

Executive Summary

Public Information and Reporting

Decisions about how, where and when to move into a residential care facility are difficult for seniors and their families even in the best of circumstances. These decisions are even more stressful, when, as is often the case, very little time is available in which to make them.

Seniors and their families need to be able to quickly and easily find pertinent, comparable and useful information about residential care facilities, so they can make informed decisions. This information should be available without having to make multiple calls, visit several websites or even turn up in various locations in person to ask questions. Without clear, accurate and objective information, it is difficult to evaluate facilities' abilities to meet their needs and interests, whether these are physical requirements, proximity to family, availability of certain therapies, or linguistic, religious, cultural or social preferences.

In the course of our investigation many seniors and their families told us that they did not have enough information available to make these important decisions. They said that in particular they would have appreciated more information about:

- eligibility criteria
- what residential care facilities are available in a community
- how placement decisions are made
- how and when residents can transfer to other facilities
- staffing levels and care standards
- dietary plans and activity schedules
- any extra charges for services
- previous complaints about the facility and how they have been dealt with
- who within a facility they can approach with a question or to resolve an issue
- who they can approach if they are dissatisfied with how a facility responds to a complaint.

Unfortunately, at this time there is no single place where seniors and their families can go to compare residential care facilities in a particular area, in order to identify an appropriate or preferred facility. While the regional health authorities provide some information, its availability and accessibility varies from one health authority to another. While some regional health authorities have developed printed guides containing information about eligibility, access to services, costs, case management and complaints processes, others have not. In some cases, guides are also available online. In other cases, health authority websites offer only general descriptions of services and contact information. As well, health

Executive Summary

authority and ministry websites can be difficult to navigate, so information can be hard to find. It may be unclear which part of a website has the relevant information and in some cases, it is scattered through several different sections. It is also disappointing to find that the information is not typically presented in a way that allows for easy comparisons between facilities and services.

I therefore recommended in Recommendation 2(a) that the ministries develop a single provincial website for the public reporting of useful information about residential care facilities and that the information be updated regularly and organized in a way that makes it easy for seniors, their families and other members of the public to search for and compare facilities. I indicated that this website should be in operation by September 30, 2010, to give sufficient time to collect and organize data.

I also recommended in Recommendation 2(a) that specific information about each facility be posted on the website, including details on funding, staffing, quality of care and standards of care. I also recommended in Recommendation 2(b) that the ministries review the evaluation model and information reporting that is to be implemented in Ontario after one year of operation to evaluate whether there are further improvements that can be made to British Columbia's public information system.

I was hopeful that the ministries would embrace these recommendations and fully accept them. I thought this would be the case partly because the provincial government seemed to recognise the importance of ensuring easy access to important information about seniors care services. For instance, in the most recent *BC Seniors' Guide*, the provincial government said, "We recognize that, as part of our commitment to building the best system of support for seniors in Canada, providing the information you need to connect with resources in your communities is key. Access to this information is equally important for caregivers and service providers."

The ministries said that they accept the intent of the Recommendation 2(a), for a provincial website to provide access to comparable detailed information about residential care facilities. They have indicated that a "Seniors' Portal," under development by the Seniors' Healthy Living Secretariat, will become a primary point of contact for public information about services for seniors. They also explained that they would work with the health authorities to improve the quality and consistency of information about residential care facilities and that the inclusion of specific information identified by the Ombudsperson as useful would be considered.

Executive Summary

While the ministries said that they accept the intent of this recommendation, this is not the same as accepting the recommendation. The proposed course of action does not set out a commitment to developing a provincial website to provide access to comparable, detailed information. This recommendation is key to ensuring that seniors and their families can make informed decisions regarding what is often their last home in British Columbia. It could also assist people in determining how their rights to health, safety and dignity, as set out in the *Residents' Bill of Rights* will be met in specific facilities. Understanding what options are available by being able to identify aspects of residential care facilities such as location, languages spoken by caregivers and other residents, types of rooms, which costs are extra, familiar food, frequency of baths, toileting policies, social activities, accommodation of spouses, the facility's policy on restraints and what specialized care is available can also reduce worry and increase confidence and satisfaction in the services delivered. Having access to a single website with comparable information about residential care facilities when you wish, where you wish, with whoever you wish present is also helpful.

Indeed accessible, useful, information allows for genuine comparisons benefits health authorities and service deliverers, whether public, private or non-profit. One of the reported strengths of different types of service delivery is "consumer" choice which leads to service improvement. This website would facilitate informed decision-making and choice. The existing information systems do not provide this. The ministries' current commitment to work with other agencies to improve standardization in some areas, sometime in the future, cannot be considered an adequate response. There is no commitment to making the website information searchable and providing a mechanism to make it easy to compare facilities. Nor is there a commitment to include the detailed information identified in the recommendation. While it is understandable to have reservations about specific information that cannot be disclosed due to legal constraints, I do not believe that is the case here. In any event, this could be fully addressed by a commitment to include the information unless it is not possible due to legal constraints.

The ministries did accept Recommendation 2(b) and have committed to reviewing the information sites in Ontario and other Canadian and international jurisdictions to evaluate and improve public information available in British Columbia. However, this will not be as useful as it could be, given the lack of commitment to implementing Recommendation 2(a).

Executive Summary

Resident and Family Councils

As already mentioned, we chose to make seniors who live in residential care facilities the focus of this first report on seniors' care, because they are the most vulnerable. After much consultation and consideration of the various possible means for improvement, we concluded that strengthening the role of resident and family councils would be both a significant positive step forward and an easily achievable one.

The benefits of resident and family councils, when properly supported, are numerous. They offer residents the chance to exercise greater influence over the conditions and decisions made about the facilities in which they live, which, while institutions, are also their homes. Through councils, residents have a collective and therefore stronger voice. Councils offer an opportunity to overcome the isolation that often accompanies life in residential care, and so may provide social and therapeutic benefits as well. They also provide a forum in which complaints and issues of concern can be aired and perhaps resolved. Often family members receive similar benefits from participating in a council.

Resident and family councils are already playing an important role in some facilities, but there is great potential for their contribution to be extended to many other facilities where they don't currently exist, and for their role to be clarified and enhanced in the facilities where they do. Our investigation team concluded that there is wide variation among the regional health authorities regarding the degree to which they support and interact with resident and family councils. I believe that the benefits of both types of councils merit a more consistent approach to their support and that the health ministries, in their stewardship role, can ensure that this is achieved. Those who would most benefit from this change are the many seniors who are not in regular contact with family or friends, and who lack anyone else to advocate for their particular interests.

I therefore recommended in Recommendation 3(a) that the ministries entrench an expanded role for resident and family councils in legislation or regulation and ensure that the change applies to all residential care facilities, regardless of which set of laws or regulations they are subject to. I specified that these changes should require that there be a designated person at each facility and in each health authority to assist and respond to resident and family councils, and that there be specific deadlines for responding to the concerns or questions raised by resident and family councils.

The ministries have expressed their general support for this recommendation and highlighted that, once in force, the *Residents' Bill of Rights* will create the right to establish and participate in a resident or family council. I am glad to see this and consider it a positive step.

Executive Summary

However, I consider it unfortunate that other aspects of our recommendation, such as the designation of a liaison person for resident and family councils at each facility and in each health authority, and the establishment of specific deadlines for responding to councils, will be enacted through policy, rather than law or regulation, particularly as there is no one applicable piece of legislation or regulation. The ministries' choice to do so means these changes will be less durable and their implementation more subject to individual discretion. This does not support greater consistency in the treatment of resident and family councils, which was the objective of the recommendation.

Due to the variations we noted in the approaches and treatment of resident and family councils across the province, I recommended in Recommendation 3(c) that the ministries establish a position to promote and develop them, and report on these activities annually. In this case the ministries have expressed their agreement with the intent of a recommendation, but have not committed to making an individual in one of the two ministries responsible for promoting and developing resident and family councils. Instead, the ministries have said they will "work with health authorities to further promote resident and family councils as an important component of a commitment to support family caregivers in all settings." It is unclear what type of new activities, if any, this will involve, or how they are to be measured or monitored. Nor is it evident that there will be somebody at the ministries that resident and family councils know will be responsible for responding to their concerns.

On a more positive note, the ministries' proposed actions demonstrate that they have fully accepted Recommendation 3(b) that they provide guidelines on how they expect operators of residential care facilities to support resident and family councils. The ministries expect to provide these guidelines to operators by March 31, 2010. Once in place, we expect that there will be more consistency in how operators respond to requests for support, interaction and information from resident and family councils.

Finally in this area, I also recommended in Recommendation 3(d) that the ministries support the establishment and development of regional family council organizations. This as well was a recommendation that came after learning that there had been stumbling blocks in some cases. The formation of regional family council organizations could serve as a needed early warning system for the ministries by allowing family councils to identify common, and perhaps systemic, problems before they become crises. Again, it is disappointing that the ministries have not committed to support the establishment and development of regional family council organizations. Rather the ministries have indicated that they will require health authorities to allow individual family council members to "participate regionally" in unspecified activities.

Background

Origins of Investigation

In early 2008, while conducting outreach tours and making presentations in different regions of the province, the Ombudsperson heard increasing public concern about a number of issues relating to the care of seniors in British Columbia. As a result, the Ombudsperson issued an advisory on June 26, 2008. It confirmed that people with concerns about the care of seniors that had not been reasonably and fairly addressed by provincial authorities could bring their complaints to the Office of the Ombudsperson. Subsequently, the Ombudsperson's office received a significant number of complaints about services for seniors from across the province.

After considering the public concern she had heard and the complaints received, on August 21, 2008, the Ombudsperson initiated a provincewide investigation to consider the provision of home support, assisted living and residential care services to seniors. Specifically, the Ombudsperson announced that the investigation would consider the issues of access to information, access to services, quality of care, standards of care, monitoring and enforcement, and complaints processes.

Seniors in British Columbia

1998: Estimated percentage of population 65+ 13% 2020: Projected percentage of population 65+ 19% 2030: Projected percentage of population 65+ 23%

5.4% of British Columbians age 65 and over live in health care facilities*

10.2% of British Columbians age 75 and over live in health care facilities*

*Includes assisted living, residential care and hospitals

BC Stats, Table 5, British Columbia Population Projections 2009 to 2036 (2009) and BC Stats, Living Arrangements of Seniors in British Columbia (2006).

The public response to this investigation has been unparalleled in the history of our office. Since initiating the investigation, we have received more than 600 responses to the questionnaire posted on our website, spoken with more than 300 people by phone, and opened more than 200 individual complaint files. Complaints have covered a wide range of issues, including

- inadequate access to information
- lack of available staff or appropriately trained staff
- delays and other problems in accessing services
- placement decisions

Background

- inadequate personal care
- poor food quality
- inadequate recreational and therapeutic activities
- extra charges for necessary items
- facility closure processes
- inadequate processes for resolving complaints.

Actions to Date

In September and October 2008, the investigation team held meetings with the Ministry of Health Services, the Ministry of Healthy Living and Sport, the Assisted Living Registrar, and with both the community care and licensing branches of the five regional health authorities. During these meetings, we discussed the respective roles and responsibilities of these agencies, their organizational structures and the policies and processes that guide the delivery and monitoring of care services for seniors. These initial meetings led to detailed requests for information and documents.

In addition, we received input from a variety of interested parties including advocacy groups, operator and employer associations, unions, family councils, care providers, private consultants and academics. Numerous written submissions were sent to us and we had meetings with more than 40 organizations and professionals in different disciplines from across the province. This process is ongoing.

Between October 2008 and March 2009, the investigation team visited 50 residential care and assisted living facilities across the province. The team toured facilities in each health authority, including facilities in rural, suburban and urban areas and facilities that were owned and operated by both public non-profit agencies and private for-profit entities. The team visited facilities that offered complex care, special care, transitional care, palliative care, acute care and assisted living services.

The Ombudsperson held meetings with the Minister of Health Services and ministry staff at the end of September 2008 and with the Minister of Healthy Living and Sport and ministry staff at the end of October 2008. At the beginning of February 2009, the Ombudsperson wrote to the ministers, outlining some preliminary results of this investigation. The Ombudsperson met again with the Minister of Health Services and the Minister of Healthy Living and Sport and their staff in mid-February 2009 to discuss those results.

Background

At the end of March 2009, the Ombudsperson provided a copy of a draft report on the preliminary results to the Ministry of Health Services and the Ministry of Healthy Living and Sport, as required by section 17 of the *Ombudsperson Act*. The report included the Ombudsperson's tentative findings and recommendations. Meetings were held with both ministries at the beginning of April 2009 to allow them to provide their initial responses for consideration by the Ombudsperson. The Ombudsperson provided a copy of her final draft to the ministries in July 2009. The ministries submitted a joint and final response to the Ombudsperson in late November 2009. The ministries' joint response is included in this report in Appendix A.

Responsibility for the Care of Seniors in British Columbia

Care for seniors in British Columbia has traditionally been treated as a health issue. Overall goals and targets are established by the provincial government. Currently the Ministry of Health Services and the Ministry of Healthy Living and Sport provide leadership, direction and support to achieve those goals through legislation, regulation and policy, as well as by directing funding to, and creating written expectations for, service delivery agencies. These ministries, in their stewardship role, set provincewide goals, standards and expectations for the delivery of services. They are responsible for ensuring good governance and continuously monitoring and evaluating the delivery of these services and program results. Stewardship requires active, effective monitoring, and frequent analysis and evaluation of information about service delivery.

Delivering care services for seniors is the responsibility of the five regional health authorities. Services are delivered either directly or through contractors. Contractors may be non-profit or for-profit organizations.

The range of care services that seniors in British Columbia may require is often described as a "continuum of care." The continuum includes primary care, acute care, home health care (day programs, home support, home care), supportive housing, assisted living, residential care and palliative care. This report focuses on issues related to residential care.

Background

Goals and Values

This section outlines the goals and values that the provincial government has stated guide the delivery of services to seniors. Care services for seniors should be consistent with the goals and core values that the province has adopted.

In 2005, the provincial government announced its five "Great Goals for A Golden Decade." One of these was to "build the best system of support in Canada for persons with disabilities, special needs, children at risk and seniors."⁴

More recently, this goal was included in the province's 2007/08-2009/10 Strategic Plan. That plan also identifies the government's "core values" as

Seniors living in residential care facilities in British Columbia

There are approximately 22,000 people in British Columbia in residential care.

Ninety-five per cent of those in residential care are people 65 or older

Fifty-two per cent of seniors in these facilities are 85 or older.

Seventy-six per cent of the people in care who are older than 85 are women.

One in seven British Columbians who is 85 or older resides in a residential care facility.

Figures and percentages based on Statistics Canada, Residential Care Facilities – 2006/2007, Table 4-11; BC Stats, Population Estimates: Standard Age Groups (2007).

- integrity: to make decisions in a manner that is consistent, professional, fair, transparent and balanced
- fiscal responsibility: to implement affordable public policies
- accountability: to enhance efficiency, effectiveness and the credibility of government
- respect: to treat all citizens equitably, compassionately and respectfully
- choice: to afford citizens the opportunity to exercise self-determination.

In September 2008, the provincial government released a document called *Seniors in British Columbia: A Healthy Living Framework*. It focused on the goal of "making British Columbia the best place on earth for older people" by "building the best system of support in Canada for our older citizens." That framework's four cornerstones are creating age-friendly communities, mobilizing and supporting volunteerism, promoting healthy living and supporting older workers.

⁴ Government of British Columbia, Speech from the Throne, 12 September 2005.

⁵ Ministry of Healthy Living and Sport, *Seniors in British Columbia: A Healthy Living Framework* (2008), 3,5.

Background

The Seniors' Healthy Living Secretariat was created on September 12, 2008, to lead the implementation of the framework. It has also been tasked with developing information services for seniors, engage with stakeholders, monitor and report on progress, and explore innovative models for providing non-medical home support services. The secretariat is part of the Ministry of Healthy Living and Sport.

Residential Care in British Columbia

Residential care facilities are described as providing 24-hour professional care in a protective, supportive environment for people who have complex health needs and cannot live safely on their own. Services include meal preparation and assistance with eating, professional nursing care, supervision and medication management. Staff also assist seniors with daily needs, including bathing and dressing.

Residential care in British Columbia is provided in a variety of ways, and by a variety of agencies, organizations and entities. Residential care may be provided in a community care facility that is licensed and regulated under the *Community Care and Assisted Living Act.*⁷ It may also be provided in

Many models of care

When accepting a space in a residential care facility, a person may end up living in

- a publicly operated facility regulated under the Community Care and Assisted Living Act
- a publicly operated facility regulated under the Hospital Act
- a privately operated for-profit facility regulated under the Community Care and Assisted Living Act
- a privately operated for-profit facility regulated under the Hospital Act
- a privately owned non-profit facility regulated under the Community Care and Assisted Living Act
- or a privately owned non-profit facility regulated under the Hospital Act.

In addition, some non-profit operators of residential care are religiously based, while others serve particular ethnic or cultural communities. Also, in some cases the staff who provide different care services within the same facility may work directly for the operator, or for a separate subcontractor.

⁶ Ministry of Health Services, *Home and Community Care Policy Manual*, Access to Residential Care, 6.B.2.

⁷ Facilities that provide residential care to three or more people must have a valid community care facility license, whether they are publicly or privately funded.

Background

an extended care hospital or a private hospital, which are licensed and regulated under the *Hospital Act*. Facilities may be publicly owned and operated or operated by private non-profit or for-profit entities.

To qualify for subsidized residential care, a person must be an adult, meet residency requirements and be assessed as unable to function independently because of chronic, health-related problems. Case management staff, employed by the regional health authorities, conduct these assessments. Each resident in a publicly subsidized residential care bed pays a per diem fee (a fee for each day), based on his or her after-tax income. In 2009, the fee was between \$31 and \$74 per day (approximately \$930 to \$2,220 per month). As of January 2010, the monthly rate for residential care clients will be 80 per cent of their annual after-tax income, as long the client can still retain an income of at least \$275 per month. The minimum client rate will be \$894.40 per month (approximately \$30 per day) and the maximum will be \$2,932 per month (approximately \$95 per day).

The per diem funding provided to residential care facilities by the regional health authorities is more difficult to determine and generally ranges from \$95 to \$262 per resident per day. Facilities may charge residents additional fees for some items and services. Residential care can also be purchased privately, with residents or their families paying the full cost of services.

Access to residential care facilities is governed by the provincial government's Access to Residential Care Policy, which is commonly referred to as the first available and appropriate bed policy. ¹⁰ In practice, this policy means that seniors seeking a place in a residential care facility are expected to accept the first bed offered to them. If the facility they are offered is not their first choice, then once placed in residential care, they can ask to be put on a waiting list to be transferred. When seniors are offered a bed in a residential care facility, they must be prepared to move into the facility within 48 hours.

⁸ To be eligible for continuing care services, a person must be a Canadian citizen or permanent resident or hold a minister's permit from the Government of Canada and have been approved by the medical advisory committee of the Ministry of Health Services. To be eligible, a person must also have resided in B.C. for the three months immediately prior to application.

⁹ Facilities receive annual funding from the regional health authorities based on the number of funded beds in the facility. The amount they receive typically includes the monthly fees that are paid by residents to the facility (between \$31 and \$74 per day). Some facilities are able to retain any portion of resident funding over \$31, while others are not. This practice does not appear to be standardized.

¹⁰ Ministry of Health Services *Home and Community Care Policy Manual*, Access to Residential Care, 6.B.

Background

The current legislative and regulatory framework in British Columbia is complicated. One of the challenges that seniors moving into residential care and their families face is understanding what rules apply to the facility they are moving into. Unfortunately, there are different regulatory schemes in place.

Legislative and regulatory provisions that are relevant to the care of seniors in residential care include the following acts and regulations:¹¹

- Community Care and Assisted Living Act
- Community Care and Assisted Living Regulation
- Residential Care Regulation
- Hospital Act.

Community Care and Assisted Living Act (CCALA)

The Community Care and Assisted Living Act, passed in November 2002, replaced the Community Care Facility Act. ¹² Under the CCALA, community care facilities must be licensed by the province. The CCALA defines a community care facility as premises or part of a premise in which care is provided to three or more unrelated children or adults. For adults, care is defined as supervision provided to an adult who is "vulnerable because of family circumstances, age, disability, illness or frailty, and dependent on caregivers for continuing assistance or direction in the form of 3 or more prescribed services."

Prescribed services are defined in section 2 of the Community Care and Assisted Living Regulation as

- regular assistance with activities of daily living, including eating, mobility, dressing, grooming, bathing or personal hygiene
- central storage of medication, distribution of medication, administering medication or monitoring the taking of medication
- maintenance or management of the cash resources or other property of a resident or person in care

Other pieces of legislation relevant to the care of seniors in residential care facilities are the *Adult Guardianship Act, Continuing Care Act* and regulations, *Health Care (Consent) and Care Facility (Admission) Act, Power of Attorney Act.* On October 15, 2008 the *Patient Care Quality Review Board Act* (S.B.C. 2008, c.35) was brought into force. It requires each regional health authority to establish a Patient Care Quality Office to receive complaints about the delivery of health care services. The Act also requires each regional health authority to establish a Patient Care Quality Review Board. Patients may complain to a review board if they are dissatisfied with the response from a Patient Care Quality Office or if they do not receive a response within 30 days.

¹² See S.B.C. 2002, c. 75, [R.S.B.C. 1996,] c. 60.

Background

- monitoring of food intake or of adherence to therapeutic diets
- structured behaviour management and intervention
- psychosocial rehabilitative therapy or intensive physical rehabilitative therapy.

The provision of prescribed services is the key distinction between residential care facilities and assisted living residences. If three or more prescribed services are provided, a facility

The provision of prescribed services is the key distinction between residential care facilities and assisted living residences.

must be licensed as a residential care facility. If only one or two prescribed services are offered, that facility is an assisted living residence and must be registered as such with the Assisted Living Registrar. An assisted living residence does not require a licence.

The *CCALA* sets out the powers and responsibilities of the provincial director of licensing, who works in the Ministry of Healthy Living and Sport. It also sets out the responsibilities of medical health officers, who are appointed under the *Public Health Act* and are employed by regional health authorities. The provincial director of licensing has overall responsibility for the provincial community care licensing program. Medical health officers are responsible for issuing licences, inspecting licensed facilities, investigating complaints, applying sanctions and issuing exemptions from requirements of the *CCALA*. In practice, these powers are often delegated to licensing officers, who work for the regional health authorities.

Section 12 of the CCALA

Private hospitals and extended care hospitals providing residential care are regulated by the *Hospital Act*, not the *Community Care and Assisted Living Act*. Consequently, different

regulatory standards, fees, monitoring and enforcement processes apply to those facilities. This is significant because rather than being offered the opportunity to choose a facility under the *CCALA* or the *Hospital Act*, people are offered placement in a facility and are expected to accept it.

Private hospitals and extended care hospitals providing residential care are regulated by the Hospital Act, not the Community Care and Assisted Living Act. Consequently, different regulatory standards, fees, monitoring and enforcement processes apply to those facilities.

Section 12 of the *CCALA* was passed on November 25, 2002, but has not yet been proclaimed and brought into force. Bringing section 12 into force would place private hospitals, extended care facilities and hospital-based continuing care facilities within the legislative framework of the *CCALA*.

Background

Residential Care Regulation

The *Residential Care Regulation (RCR)* was passed on March 12, 2009 and came into force on October 1, 2009, repealing and replacing the *Adult Care Regulations*, as well as the residential aspects of the *Child Care Licensing Regulation*.

The *RCR* establishes standards for physical requirements, including bedrooms, bathrooms, common areas and work areas. The regulation sets out requirements for staffing, admissions, care, nutrition, medication, use of restraints and reportable incidents. The *RCR* includes a requirement for the licensee to provide an opportunity for persons in care and their representatives and family members to establish a resident and family council. The *RCR* also sets out records management requirements.

The new *RCR*, which also applies to children and youth in residential care, increases the requirements that residential care facility staff have to meet. Under the *RCR*, employees have to provide a criminal record check, character references, work history and proof of relevant training. Facility operators have to regularly review the performance of staff and ensure that employees do not carry out duties which they are not competent to perform. Employees are also prohibited from smoking on the premises of residential care facilities.

The new *RCR* also requires more frequent recording of incidents and health concerns. For instance, facility operators previously were required to track only those medication errors that adversely affected the patient. Under the new *RCR*, all medication errors must be recorded. Increased reporting measures also apply to the use of restraints and occurrences of communicable diseases. Under the *RCR*, facility operators are also required to develop a fall-prevention plan for any resident who may be prone to falling.

The new *RCR* requires operators to place a bracelet or other secure means of identification on those who are judged to be at risk of leaving the premises without alerting staff, and of not being able to identify themselves. The bracelet must give the name of the person and the community care facility as well as emergency contact information.

The new regulation requires the dignity of persons in care be considered when determining care standards. In particular, the dignity of the individual is to be considered by operators when assessing the adequacy of privacy, furniture and equipment in bedrooms and bathrooms. Staffing must also be sufficient for individuals to receive care in a manner consistent with their dignity. However, how "dignity" will provide a measurable standard has not been specified.

Background

Hospital Act

Private hospitals that provide residential care services are regulated by part 2 of the *Hospital Act*.¹³ Private hospital is defined in part 2 to mean, "a house in which 2 or more patients, other than the spouse, parent or child of the owner or operator, are living at the same time, and includes a nursing home or convalescent home, but does not include a hospital as defined in section 1."

Private hospitals must be licensed in accordance with the *Hospital Act*. Unlike the *Residential Care Regulation*, the *Hospital Act* has no mandatory standards for operators who provide residential care. It only requires that the "house" be approved by the provincial chief inspector of hospitals, who is an official in the Ministry of Health Services, as suitable for the purpose indicated in the application for licensing. The *Hospital Act* also states that a licensed private hospital may be inspected "at any time" by a hospital inspector who is employed by a regional health authority.

Residential care can also be provided as "extended care" in a hospital setting, in which case it is also subject to the *Hospital Act*. The definition of hospital in the *Hospital Act* includes, "a non-profit institution that has been designated as a hospital by the Minister of Health Services and is operated primarily for the reception and treatment of persons requiring extended care at a higher level than that generally provided in a private hospital licensed under Part 2."

Private hospitals and extended care hospitals are often either part of a general hospital or near a general hospital. There are advantages and disadvantages associated with *Hospital Act* regulation. For example, while many seniors in private hospitals and extended care hospitals are not required to pay for over-the-counter medications and some medical supplies, most seniors in residential care facilities regulated under the *CCALA* are required to do so. *Hospital Act* facilities also seem to have greater access to hospital supplies, equipment and resources. However, generally these facilities tend to look more like hospital wards, with more people per room than *CCALA* facilities. Another disadvantage is that these facilities are not subject to the same requirements and oversight as facilities that are subject to the *CCALA*.

¹³ Hospital Act, R.S.B.C. 1996, c. 200.

Commitment to Care and Residents' Rights

"Some of the staff are responsive and understand that the family wants a level of dignity for the resident and others don't seem to get that. We don't feel there is a consistency to their policies on the level of care." ¹⁴

What We Heard

Between August 2008 and December 2009, more than 600 people contacted our office to

Delays in responding to call buttons

"No one answered the bell when I needed help...I finally went out into the hallway and called for help. The staff person who answered said...they don't have enough people to answer the bell right away."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

provide input into the investigation and share their concerns. More than 200 other people made complaints about their care, or that of a family member or friend. The Ombudsperson's office is conducting separate investigations into these complaints. Some examples of the input and complaints we received are provided in this section.

In the course of our investigation, we heard from concerned seniors and their families who did not feel they had an adequate understanding of the level of care that seniors are entitled to receive in residential care facilities. People told us that they were reluctant to

raise concerns about the level of care that facilities provide, in part because they were not confident about what residents were entitled to receive or what their rights were. They said they felt vulnerable and worried, whether justifiably or not, about raising concerns because residents were dependent on others for their care. In general, people did not have a good understanding of the legal obligations of facility operators.

Poor quality food

"The food has been dreadful. There is...a lack of awareness that food is the one pleasure left..."

"There is never any fresh vegetables and rarely fresh fruit..."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

We also heard from seniors, their families and family councils that it could be difficult to determine who was responsible for the delivery of specific services and with whom concerns about these services could be raised. This was especially true when service delivery was contracted out to third parties.

¹⁴ Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

Commitment to Care and Residents' Rights

In addition to hearing that people did not understand the level of care that seniors in residential care facilities are entitled to, or should expect to receive, we observed variation in

the services offered in residential care facilities across the province.

Between October 2008 and March 2009, the Ombudsperson's systemic investigation team visited residential care facilities across the province.

Facilities visited varied widely in terms of physical conditions, staffing levels, food services, service delivery models and philosophical approaches to care.

Delays in getting help with going to the bathroom

"The staff seem dedicated and caring....[but] my mother sometimes waits 30-40 minutes for help getting off the commode...."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

Some facilities had only one resident per room and private bathrooms. In others, two to four people shared a room and a bathroom. Some facilities prepared food on-site while others prepared it elsewhere and only heated it on-site. Some facilities had adopted a person-centred model of care, while others followed a medical model of care. Charges for everything from support equipment to social activities varied.

Delays in changing soiled linens

"My mother has dementia...in most cases she does not know what she wants... you can smell the odour...Her bedding is soaked with urine."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

Many people who contacted our office to provide input told us they did not want us to investigate their concerns because they involved events that had occurred some time ago. Although they were matters that still bothered these individuals, realistically, they accepted that no current investigation could

resolve them. In other cases, people told us they did not want us to look at the specific instance they raised because they feared, rightly or wrongly, that this would negatively affect the care that they or their loved ones were receiving.

When we raised some of these concerns with the Ministry of Health Services and the Ministry of Healthy Living and Sport, they told us that if these concerns were raised with

facility operators and regional health authorities, the ministries expected such concerns would have been taken seriously. The ministries told us these were the type of concerns that if substantiated, should have resulted in

Inadequate cleaning and laundry services

"I have found old dried feces on the rails of my father's bed, dried mucus on the floor..."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

Commitment to Care and Residents' Rights

rapid response and specific remedial action. They said these were the types of concerns that if not appropriately dealt with by the facility or health authority, the ministries wanted to hear about, so that they could ensure appropriate action was taken.

It is difficult, however, for people to persevere with their concerns and complaints if they do not know what their rights are and what treatment they can reasonably expect from a residential care facility. It can be challenging to obtain a timely response or adequate remedial action.

While the ministries made strong statements about the steps they would take if these types of concerns were raised with them, our investigation yielded many examples of the

Staffing shortages

"My aunt...agreed to go to bed at 4 p.m. due to a shortage of evening staff."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

difficulties that people often have in obtaining a timely response and adequate remedial action. In such cases, we believe that the people affected would have benefited from having clear and enforceable rights set out in a single, understandable and easily obtainable document.

Unclear Understandings of Care Expectations

While some people only wanted to provide input to our investigation, many others made specific complaints. Below are two examples of complaints we received that illustrate the problems that result when expectations about care are unclear.

Murray's Story

Murray complained for more than four months about the quality of food and food services in the care facility where his elderly parent lived. ¹⁵ He directed these complaints to both the facility's operator and the regional health authority. He complained about his parent not receiving food requested from the menu, unpalatable food and cold meals. The following excerpt is from one of a number of e-mails he sent to the health authority:

This is an extended care facility. This is the home for those residents who are there. They cannot fend for themselves. A hot cup of coffee or tea is a real luxury for them and certainly, not too much to ask.

¹⁵ Names have been changed to protect confidentiality.

In this situation, the family council provided support to Murray and advocated for improved services for all the residents. The council was able to demonstrate the validity of these concerns. The council determined that the food at the facility was provided by a contractor that was preparing the food off-site and reheating it at the facility. The council was able to reinforce that residents should receive quality food and a range of food choices. However, their concerns had to be taken to the highest level of the health authority before the facility responded adequately. Food is now cooked on-site at this facility.

If there had been a bill of rights that clearly defined residents' rights to proper food and to live in an environment that promoted their health, safety and dignity, Murray and his parent would have been able to assert these rights when complaining to the facility and the health authority. Had this been the case, we believe it would have been easier to resolve this situation.

Emily's Story

People in residential care facilities receive their medications from facility staff. Emily wrote to the CEO of a health authority about her concerns after her mother experienced five medication errors in less than a year. ¹⁶ In the letter she asked:

How would you feel to know that your loved one in a care facility had received incorrect... medications on five separate occasions in less than a one year period of time?

Emily went to the CEO only after raising her concerns with the facility and health authority staff. As the medication errors were continuing, Emily was not reassured by assertions that improvements had been made to prevent future problems.

With the ongoing support and involvement of the family council, Emily continued to voice her concerns. About eight months after writing to the CEO, health authority staff wrote to inform her that they had completed a "quality review" of the medication errors her mother had experienced and that 11 recommendations for improvement to the processes for dispensing medication at the facility had been made.

If there had been a bill of rights in British Columbia that specifically established a right to be protected from abuse and neglect, Emily would have been able to assert this right in her complaints to the facility and the health authority. In that situation, we believe it would have been easier and faster to resolve this serious situation and put measures in place to ensure that it did not recur.

¹⁶ Names have been changed to protect confidentiality.

Models in Other Jurisdictions

Canadian Provinces

Saskatchewan and Manitoba have regulated the rights of seniors in residential facilities.¹⁷ Ontario passed the *Long-Term Care Homes Act* in 2007, which is scheduled to come into force as soon as supporting regulations are complete.¹⁸ The *Long-Term Care Homes Act* contains statutory provisions that outline the rights of residents in care facilities, in a section titled, "Residents' Bill of Rights." Ontario's legislation, when it comes into force, will make the residents' rights directly enforceable against a facility and will confirm that the legal rights of all citizens continue to be enjoyed by seniors who are living in residential care facilities. The Ontario *Long-Term Care Homes Act* states that residents of long-term care homes have the right

- to be treated with courtesy and respect
- to be protected from abuse
- to not be neglected by the operator or staff
- to be properly sheltered, fed, clothed, groomed and cared for
- to live in a safe and clean environment
- to exercise the rights of a citizen
- to be told who is responsible for and who is providing the resident's direct care
- to be afforded privacy in treatment and in caring for his or her personal needs
- to have his or her participation in decision-making respected
- to keep and display personal possessions, pictures and furnishings in his or her room
- to participate fully in all aspects of his or her health care
- to receive care based on a philosophy to maximize independence
- to not be restrained, except in limited circumstances
- to communicate in confidence, receive visitors and consult in private with any person

¹⁷ Personal Care Homes Regulations, 1996, R.R.S., c. P-6.01 Reg. 2, ss. 34, 34.1, 35 (Personal Care Homes Act, S.S. 1989-90, c. P-6.01) Personal Care Homes Standards Regulation, Man. Reg. 30/2005, part II (Health Services Insurance Act, C.C.S.M. c. H35).

¹⁸ The Act received royal assent on June 4, 2007. At the time this report was being published, it had not yet come into force. The Ontario government is in the process of circulating draft regulations, which are to be completed before the Act comes into force.

- to have family and friends present 24 hours per day if the resident is very ill
- to designate a person to get information about any transfer or any hospitalization
- to raise concerns with the resident council, the family council, the care home, the government, and any other person inside or outside the long-term care home
- to form friendships and relationships
- to participate in the life of the care home
- to have his or her lifestyle and choices respected
- to participate in the resident council
- to meet privately with his or her spouse or another person
- to share a room with another resident according to their mutual wishes, if appropriate accommodation is available
- to pursue social, cultural, religious, spiritual and other interests
- to be informed in writing of any law, rule or policy affecting services and of the procedures for initiating complaints
- to manage his or her own financial affairs unless the resident lacks the legal capacity to do so
- to be given access to protected outdoor areas in order to enjoy outdoor activity unless the physical setting makes this impossible
- to have any friend, family member or other person attend any meeting with the owner or operator of the care home.

Quebec introduced *An Act respecting health services and social services* (*ARHSSS*) in 1991.¹⁹ It sets out a framework to foster access to health care and social programs, protect individual autonomy and ensure quality of services. The *ARHSSS* applies to seniors in any part of the health system, including residences for the elderly, residential care facilities and hospitals.

Under the ARHSSS, residents have the right

- to be informed of the existence of the health and social services and resources available in the community, and of the conditions governing access to such services and resources
- to receive, with continuity and in a personalized and safe manner, health services and social services which are scientifically, humanly and socially appropriate

¹⁹ An Act respecting health services and social services, R.S.Q. c. S-4.2.

Commitment to Care and Residents' Rights

- to choose the professional or the institution from whom or which he or she wishes to receive health services or social services
- to receive the care required by his or her condition
- to be informed of his or her state of health and welfare and to be acquainted with the various options open to him or her and the risks and consequences generally associated with each option before giving his or her consent to care
- not to undergo care of any nature, whether for examination, specimen taking, treatment or any other intervention, except with consent
- to participate in any decision affecting his or her state of health or welfare including the development of an intervention plan or individualized service plan
- to be accompanied and assisted by the person of his or her choice when obtaining information or taking steps in relation to any service provided by an institution.

United States

In the U.S., the federal *Nursing Home Reform Act* (also known as the *Omnibus Budget Reconciliation Act of 1987* or *OBRA 87*) sets national minimum standards of care and establishes rights for people living in certified Medicaid and Medicare nursing homes. The Act establishes the following rights for nursing home residents:

- the right to freedom from abuse, mistreatment, and neglect
- the right to freedom from physical restraints
- the right to privacy
- the right to accommodation of medical, physical, psychological, and social needs
- the right to participate in resident and family groups
- the right to be treated with dignity
- the right to exercise self-determination
- the right to communicate freely
- the right to participate in the review of one's care plan, and to be fully informed in advance about any changes in care, treatment or change of status in the facility
- the right to voice grievances without discrimination or reprisal.

Since 1987, a number of states have taken all or part of this legislation and made it state law.

Commitment to Care and Residents' Rights

The Situation in British Columbia

At the Beginning of Our Investigation

As discussed in the previous section, a number of different acts and regulations govern the provision of residential care in British Columbia. While these acts and regulations impose obligations on facility operators, none clearly set out the government's commitment to care or the rights of all seniors in residential care facilities in a straightforward, understandable and resident-focused manner.

This approach did not make it easy for people to understand what they were reasonably entitled to expect in terms of treatment, facilities and services. We concluded that a clear understanding of what the government's commitment to care is — what residents' rights are — would assist not only residents and their families, but also health authority staff and facility staff.

What do we mean by a commitment to care and the rights of residents? A commitment to care is the government's commitment to ensuring that seniors in residential care facilities receive care that meets their needs. Residents' rights means the rights that all people in British Columbia have, which must continue to be respected when they move to a residential care facility, as well as the specific rights that would be accorded to residents in facilities.

It would reduce misunderstandings and miscommunications and facilitate consistency of expectations and service delivery.

The legislative and regulatory frameworks in place at the outset of this investigation did not clearly communicate the government's intentions about many crucial issues that affect seniors in residential care. These issues included whether residents have the right to

- assistance with basic needs such as eating, moving around and going to the bathroom
- be told who is responsible for providing direct care
- participate in decision-making concerning any aspect of care
- communicate in confidence and meet and receive visitors in private
- have visitors 24 hours a day if they are very ill or dying
- pursue social, cultural, religious, and spiritual interests
- form relationships
- be informed of services available in the community
- access protected outdoor areas
- care by people who speak their language

Commitment to Care and Residents' Rights

- prompt medical treatment
- participate in a resident council
- be informed of how to address concerns or make a complaint
- enforce their rights against an operator.

Some residential care facilities have developed their own internal statement of residents' rights. However, when we began this investigation, no such statement of rights for all seniors in all types of residential care existed for the province as a whole. It was therefore not surprising that seniors in residential care facilities and their family members were not sure what care they were entitled to receive and how to proceed when they had concerns about the adequacy of services. We concluded that an important step toward remedying this problem would be for the government to embed its commitment to care and the rights of people living in residential care facilities in law. We believed that creating a commitment to care in the form of a residents' bill of rights would encourage consistency of care and make it clear to residents, relatives, facility operators, facility staff and others that when seniors walk through facility doors into their new homes, they do not lose their rights to make decisions, exercise independence, be treated with respect, vote, enjoy religious freedom or participate in the community. Rather, residents gain rights to care and security.

Further, we believed that creating a bill of rights would provide seniors with greater awareness and certainty about the level of care they could expect to receive in a residential care facility. We also believed that this would help people understand their entitlement to care, and could result in complaints and concerns being identified and examined more quickly. We believed that enacting a residents' bill of rights would be consistent with the goal of "making British Columbia the best place on earth for older people" by "building the best system of support in Canada for our older citizens." ²⁰

The Current Situation

The Ombudsperson raised the idea of creating a bill of rights for seniors in residential care with the Minister of Health Services and the Minister of Healthy Living and Sport at the beginning of February 2009. In November 2009, Bill 17, the *Health Statutes (Residents' Bill of Rights) Amendment Act, 2009* (See Appendix B) was passed. When brought into force, it will establish, in law, the rights of seniors and other adults in all residential care facilities in British Columbia. The *Residents' Bill of Rights* will apply to all facilities in which

Ministry of Healthy Living and Sport, Seniors in British Columbia: A Healthy Living Framework (2008), 3. It is notable that the provincial government has created a clear statement of rights to govern other areas. An example is the Ministry of Transportation's "Taxi Bill of Rights" for taxi passengers in the Metro Vancouver area, which took effect in January 2008.

residential care is provided, whether that is done in extended care or private hospitals under the *Hospital Act* or residential care facilities under the *Community Care and Assisted Living Act*. Operators will be required to post a copy of the rights in a prominent place in their facilities, and to make the rights known, orally and in writing, to residents and their representatives.

In order to ensure that the *Residents' Bill of Rights* is meaningful to residents and families, it will be important for the ministries to monitor and evaluate the degree to which these rights are respected and to report the results of that monitoring and evaluation publicly. This is crucial because seniors in residential care are vulnerable and, in many cases, have limited capacity to make and follow through on complaints when their rights are not respected. As well, establishing reliable and objective monitoring processes would allow those responsible for ensuring that the rights are respected to know whether and to what degree facilities are complying with the *Residents' Bill of Rights*. Ongoing monitoring and evaluation would show how individual facilities deal with complaints about rights not being respected and point to any areas of concern. Making this information public would be useful to residents and family members and allow them to compare the performance of various facilities.

Ombudsperson Finding

(1) The Ministry of Health Services and the Ministry of Healthy Living and Sport have not adequately identified the province's commitment to care and the rights of seniors in residential care facilities.

Ombudsperson Recommendations

- 1(a) The Ministry of Health Services and the Ministry of Healthy Living and Sport take the necessary steps to ensure that a commitment to care and the rights of seniors living in all residential care facilities are set out clearly in law by March 31, 2010.
- 1(b) The Ministry of Health Services and the Ministry of Healthy Living and Sport require all residential care facility operators to post the commitment and the rights at the entrance to the facility where it is easily visible to residents and visitors.
- 1(c) The Ministry of Health Services and the Ministry of Healthy Living and Sport develop a reliable and objective process to monitor and evaluate the degree to which residents' rights are respected.
- 1(d) The Ministry of Health Services and the Ministry of Healthy Living and Sport publicly report the results of this monitoring and evaluation annually, commencing in 2011.

Public Information and Reporting

"So many of these decisions have to be made in very difficult and urgent circumstances. So even though we had done some research ahead of time, when decisions had to be made, it was very difficult to figure out what our options were, if any."²¹

Decisions about how, where and when to move into a residential care facility are difficult for seniors and their families even in the best of circumstances. These decisions are even more stressful, when, as is often the case, very little time is available in which to make them. To make informed decisions, seniors and their families need reliable, publicly available information, as well as the input provided by their physicians and other health professionals.

As discussed earlier in this report, residential care facilities may be operated in a variety of ways, including by regional health authorities, or private non-profit or for-profit entities. Services, too, may be provided in a variety of ways. In some facilities, food is prepared in an on-site kitchen, while others bring prepared food in from elsewhere. The staff who provide personal care, cleaning and food services might be employed directly by the facility's operator or by sub-contractors. Rooms and bathrooms may be private or shared.

Seniors and their families need to be able to quickly and easily find pertinent, comparable and useful information about residential care facilities, so they can make informed decisions. This information should be available without having to make multiple calls, visit several websites or even turn up in various locations in person to ask questions. When differences in facilities can be compared, and when reasons for differences are explained, seniors and their families are better able to make decisions that best suit their needs and circumstances. Without clear, accurate and objective information, it is difficult to evaluate facilities' abilities to meet their needs and interests, whether these are physical requirements, proximity to family, availability of certain therapies, or linguistic, religious, cultural or social preferences.

The Current Situation

Information about Residential Care Provided by the Provincial Government

To be eligible for placement in a subsidized residential care facility a senior must agree to accept the first available and appropriate bed and must occupy the bed within 48 hours of when it was offered. In offering placements, case managers may consider a number of factors, such as bed availability, client preferences and suitability from a clinical perspective. Once a senior has accepted a placement, he or she can put his or her name on a waiting list

²¹ Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

32 OFFICE OF THE OMBUDSPERSON

Public Information and Reporting

for placement in his or her facility of choice. Having access to information about residential care facilities is critical for seniors when they are identifying their preferred facilities, deciding whether to accept a placement and whether to request a transfer.

At this time, there is no single place where seniors and their families can go to compare residential care facilities in a particular area, in order to identify an appropriate or preferred facility.

While the provincial government provides some information about residential care to the public through the Ministry of Health Services and the Ministry of Healthy Living and Sport, currently, it is the regional health authorities that provide most of this information. Its availability and accessibility varies from one health authority to another. While some regional health authorities have developed printed guides containing information about eligibility, access to services, costs, case management and complaints processes, others have not. In some cases, guides are also available online. In other cases, health authority websites offer only general descriptions of services and contact information.

Health authority and ministry websites can be difficult to navigate, so information, even where available In the most recent BC Seniors' Guide, the provincial government made the following statements about the importance of providing information to the public about health services:

"We recognize that, as part of our commitment to building the best system of support for seniors in Canada, providing the information you need to connect with resources in your communities is key. Access to this information is equally important for caregivers and service providers."

"We have accessible and affordable health services that respond to the needs of seniors, and we are committed to making it easier for residents to find the information they need about programs and services that apply to them. Being aware of what's available is the first step to enjoying improved health services."

See Ministry of Health Services, *BC Seniors' Guide* (9th edition, 2008-09), 1, 25.

and of good quality, can be hard to find. It may be unclear which part of a website has the relevant information and in some cases, it is scattered through several different sections.

In addition, the information is not typically presented in a way that allows for easy comparisons between facilities and services. People who are deciding which facility might be most appropriate for themselves or a family member must contend with inconsistent information on specific facilities.

We identified some particular gaps in the information provided:

Public Information and Reporting

Different governing acts: The information we reviewed does not identify whether facilities are governed by the *Community Care and Assisted Living Act* or by the *Hospital Act*. This is a problem because the difference can affect what residents will pay for. As well, the different acts have different inspection and reporting requirements.

Policy on access to residential care: This policy requires individuals to accept a placement in the facility when the first available and appropriate bed becomes available. The publicly available information does not define "appropriate." More information regarding how the ministries expect this policy to be applied would help prospective residents better understand the placement process. It would also help them to participate more effectively in the selection process and to focus their concerns and complaints when they disagree with a case manager's decision about which facility is appropriate.

Even when clear and detailed information exists, it can only help those who know where and how to access it. During the course of this investigation, we have frequently heard that seniors and their families find it extremely frustrating and challenging to learn all they need to about residential care in the limited time available to them prior to placement.

Community Care Inspection Reports

On November 18, 2008, as a result of direction from the then-Ministry of Health, the province's five regional health authorities began to post inspection reports for care facilities licensed under the *Community Care and Assisted Living Act* on their websites.²² The regional health authorities now list when facilities have failed to meet regulatory requirements and note when and if issues have been resolved.

Making these inspection reports publicly available was a positive step forward, but

Making these inspection reports publicly available was a positive step forward, but not all residential care facilities are licensed under the Community Care and Assisted Living Act. Facilities licensed under the Hospital Act are not subject to the same oversight and inspection by the health authorities and inspection reports for these facilities are not posted on the health authorities' websites.

not all residential care facilities are licensed under the *Community Care and Assisted Living Act*. Facilities licensed under the *Hospital Act* are not subject to the same oversight and inspection by the regional health authorities and inspection reports for these facilities are not posted on the health authorities' websites. This makes it impossible for the public to

²² As a result of government re-organization on June 23, 2008 the Ministry of Health was divided into the Ministry of Health Services and the Ministry of Healthy Living and Sport.

Public Information and Reporting

compare all residential care facilities based on the same criteria. Unfortunately, none of this is explained anywhere on the websites where the inspection reports are posted, so it is not clear to the public that the reports do not cover all residential care facilities in the province.

As well, the information in the inspection reports is brief, and not presented in a way that is likely to be easily understood by, or particularly useful to, seniors or their families. This is not surprising, since the inspection reports are primarily for use by health authority staff. It does mean, however, that the reports alone are not an adequate source of public information about care standards and service quality. As well, the contents of the reports are often limited. The reports provide information regarding standards that are not met, and may outline requirements for corrective actions that should be taken to address outstanding concerns. However, the reports typically do not provide much detail about the problem. For example, an inspection report may indicate "hazardous practice observed" or "administration or handling of medication does not meet requirements" but not provide further information.

February 2009 Home and Community Care Directive

The Ministry of Health Services appears to have recognized that there is a need for more information about residential care services and facilities. In February 2009, the Ministry of Health Services issued a directive that requires the regional health authorities to make more information about home and community care services, including residential care, available to the public. This will be done in accordance with a prescribed format that was to be provided to the regional health authorities by March 30, 2009.²³ The information that each health authority will be required to provide to the public about each facility in its region includes

- addresses and contact information
- the number of publicly funded beds
- current services and activities
- philosophy of care
- accreditation status
- restrictions or rules
- language
- cultural and religious affiliation, if applicable
- any additional amenities.

²³ In fact, the prescribed format was not finalized until after June 2009.

Public Information and Reporting

In addition, the regional health authorities must provide information to the public about

- how to access community programs and facility-based care
- intake and screening processes
- how to make a complaint about home and community care services, including review processes
- the health authority's performance in ensuring quality care and standards of care.

At the time that this report was published, the regional health authorities had not complied with all the terms of this directive. We were informed that the goal is to make the information available as of December 2009.

While issuing these requirements is a step in the right direction, we believe that the provincial government should do more to make useful and comparable information about residential care services accessible to the public. In fact, and as we will discuss later in this section, there are several effective public information reporting models for residential care facilities already functioning in other North American jurisdictions.

What We Heard

As part of our investigation, we posted online and distributed a questionnaire that included the question, "Do you have access to enough information to make informed decisions about care?" Overwhelmingly, respondents said they did not feel that they did. We heard similar concerns when we visited residential care facilities.

Specifically, seniors and their families told us they wanted more information about

"Other than being taken on a brief 'tour' of the facility, which is very superficial, and does not address core issues such as staffing levels, quality of food, quality of life issues such as music and recreation therapy services, availability of physio/occupational therapy, etc., there is no access to relevant information prior to placement of a loved one."

Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

- eligibility criteria
- what residential care facilities are available in a community
- how placement decisions are made
- how and when residents can transfer to other facilities

Public Information and Reporting

- staffing levels and care standards
- dietary plans and activity schedules
- any extra charges for services
- previous complaints about the facility and how they have been dealt with
- who within a facility they can approach with a question or to resolve an issue
- who they can approach if they are dissatisfied with how a facility responds to a complaint.

Lack of Information About Facilities

We are providing two examples of the complaints that we received about the lack of available information about care facilities. Both these situations illustrate the importance of having timely access to information when making decisions about how and where seniors will be cared for.

Marilyn's Story

Marilyn came to us because she didn't think her health authority had given her or her mother enough information to make a decision about her mother's placement in a residential care facility.²⁴

After a re-assessment, a case manager had decided that the care needs of Marilyn's mother had increased to the point that she could no longer live in her assisted living unit. The case manager told Marilyn that she would seek placement for her mother in a residential care facility. Marilyn told us that she understood from her conversation with the case manager that when her mother came to the top of the waiting list, she would be placed in the first bed that became available in the community. Marilyn explained that neither she nor her mother were asked to identify the residential care facility they preferred.

When Marilyn's mother was offered a placement, Marilyn visited the facility. During her visit Marilyn found that the residents were less active and aware than her mother. Marilyn was also told that her mother would be sharing a room and bathroom with two or three other residents. She did not feel the placement was suitable for her mother.

²⁴ Names have been changed to protect confidentiality.

Public Information and Reporting

Marilyn was also concerned that her family had been given only 24 hours to decide whether to accept the placement and 48 hours to make the necessary moving arrangements. She was unclear what would happen to her mother if they turned down the placement, and did not know how doing so would affect her mother's priority on the waiting list.

Marilyn contacted the Office of the Ombudsperson to complain about the adequacy of this process and the lack of information she and her mother had been given. We explained that under the current provincial policy, the availability of a bed was not the only criteria and that the bed offered must also be appropriate. Marilyn later spoke with the health authority about her concerns, and her mother was then offered a different and more appropriate placement, which she accepted.

If there had been a single provincial website that provided useful and comparable information about the residential care facilities in Marilyn's community, the services they offered, and the placement process, Marilyn's family would have been in a better position to identify an appropriate facility for her mother.

Diane's Story

Diane was a 91-year-old woman who had lived independently until she fell and broke her hip.²⁵ Complications following surgery meant she had to stay in the hospital for three months. Once she was able to walk short distances with a walker, hospital policy said she was ready to be discharged. As Diane could no longer live safely in her home, she was placed on the waiting list for transfer to a residential care facility.

Diane's daughter took her home from the hospital for the weekend and planned to return her there the following Monday. However, the roads were treacherous on that Monday morning because it had snowed the night before. Diane's daughter called the hospital to let them know she would be late returning her mother. She was then told that Diane was to be moved to a residential care facility that afternoon.

Diane's daughter was given the name of the facility, but no other information. After her husband quickly visited the facility to learn more about it, it became apparent to him that it was not an appropriate facility for his mother-in-law since, among other things, it did not provide the rehabilitation that the whole family, including Diane, believed would be important to Diane's well-being.

²⁵ Names have been changed to protect confidentiality.

Public Information and Reporting

Diane's daughter called the hospital again but was unable to obtain adequate information about other options. She also contacted our office to express her concern about this and other issues relating to her mother's assessment. Ultimately, because of concerns about the suitability of the placement, Diane's daughter decided to bring her mother into her own home, in order to facilitate her rehabilitation.

If there had been a single provincial website that provided information about the residential care facilities in Diane's community and the services they offered, Diane's family would have had an easier time accessing the information they needed.

Models in Other Jurisdictions

Ontario and California provide two useful models of public reporting about residential care because their systems are considered to be inclusive and user-friendly.

California

What we in British Columbia call residential care facilities are known as nursing homes in California.²⁶ Since 2002 the California HealthCare Foundation website has provided comprehensive information about nursing homes including information about staffing, quality of the facility, quality of care, finances and costs.²⁷ Data comes from state and federal government sources and is updated quarterly.

The California model is an example of public reporting that provides potential and current residents and their families with meaningful and comparable information about the quality of life in particular nursing homes. These evaluation processes and the information that results may also be useful to policy-makers.

Ontario

The equivalents of British Columbia's residential care facilities are called long-term care homes in Ontario.

²⁶ In California, the term "residential care" refers to services and housing for those who do not need skilled nursing and who are able to live independently. California's residential care services are similar to British Columbia's assisted living services. California's "residential care facilities for the elderly" provide non-medical care for those aged 60 and over who require help with activities such as bathing.

²⁷ California HealthCare Foundation, <www.calqualitycare.org> (2009).

Public Information and Reporting

Ontario's Ministry of Health and Long-Term Care maintains a website called Reports on Long-Term Care Homes.²⁸ One part of the website provides general information about long-term care homes in Ontario, including how they are operated, who owns them, accommodation options, basic services provided, optional services available, costs, subsidies, applicable legislation, monitoring and how to make a complaint.

The website also contains a searchable database of all long-term care homes in Ontario and includes information about each facility under the headings "home profile," "inspection findings" and "verified complaints."

The profile of each long-term care home in Ontario provides the following information:

- the name of the home's administrator and operator
- the type of operator
- the management firm, if applicable
- the home's structure and number of beds
- whether there are approved short-stay beds
- whether there is a resident or family council
- whether the home is designated under the French Language Services Act
- whether the home is accredited
- the date of the last inspection.

Information gathered during provincial inspections is included in the inspection findings section of the website. Inspection findings and verified complaints for each long-term care home are posted for 12 months, with comparisons against the provincial average for the same period. The website gives the date of the last inspection, the number of unmet standards and criteria, the number of citations, sanctions or enforcement steps taken and the types and total number of verified complaints.

Under the "inspection findings" heading, the following categories of unmet standards and criteria are listed for each home:

- resident safeguards
- resident care and services
- nursing services
- staff education

²⁸ Ontario Ministry of Health and Long-Term Care, *Reports on Long-Term Care Homes*, http://www.health.gov.on.ca/english/public/program/ltc/26_reporting.html>.

Public Information and Reporting

- recreation and leisure services
- social work services
- spiritual and religious programs
- therapy services
- volunteer services
- dental services
- foot care services
- other approved programs
- facility organization and administration.

While this is much more information than currently provided by the British Columbia government, a recent report, known as the Sharkey report, was still critical of Ontario's current reporting system and concluded it did not include enough information.²⁹ The report recommended, "strengthening accountability in LTC [long-term care] homes by linking resources to resident outcomes... [and] implementing measures to enable public reporting and to develop quality measurement tools and satisfaction surveys."³⁰ In particular, the report recommended the development of standardized measures to address and report on resident quality-of-care outcomes (based on indicators such as functional status, continence, falls, wounds, pain, nausea and breathing discomfort), resident and family satisfaction, and staff satisfaction and engagement.

The government of Ontario has adopted the Sharkey report's general recommendations on public reporting. The Ontario Health Quality Council is currently developing a mechanism for measuring quality of care and resident satisfaction in long-term care homes. Once completed, long-term care homes will be evaluated using that mechanism and the information will be publicly reported. The public reporting is currently scheduled to commence in mid-December 2009.³¹

²⁹ Ontario Ministry of Health and Long-Term Care, People Caring for People: Impacting the Quality of Life and Care of Residents of Long term Care Homes: A Report of the Independent Review of Staffing and Care Standards for Long-Term Care Homes in Ontario (2008).

³⁰ Ontario Ministry of Health and Long-Term Care, *People Caring for People: Impacting the Quality of Life* and Care of Residents of Long term Care Homes, 11.

³¹ The Ontario Health Quality Council is taking a voluntary approach in its first year of posting information. It expects that all LTC homes in Ontario will be measuring and publicly reporting on all required quality indicators in 2011.

Public Information and Reporting

Conclusion

Seniors and their families need and should have access to useful information when they are making critical decisions about residential care and throughout the period of residence in facilities. For example, it should be easy to find out what residential care facilities are in a community, how may subsidized and private pay beds they have, whether rooms are private or shared and what services are offered. While posting regulatory infractions online is a useful starting place, more detailed public reporting on a range of other criteria needs to be undertaken. Other jurisdictions have shown this is possible.

Increasing the amount of information about residential care that is publicly available is also consistent with the provincial government's core values of integrity, respect and choice. Making more information available would also help residents and families monitor the quality of care and assist them when advocating for changes at a particular residence. It would increase accountability within the system.

Ombudsperson Finding

(2) The Ministry of Health Services and the Ministry of Healthy Living and Sport have not ensured that adequate information about residential care facilities is publicly available in an accessible format that allows seniors and their families to plan for and make informed decisions about residential care.

Ombudsperson Recommendations

2(a) The Ministry of Health Services and the Ministry of Healthy Living and Sport develop a single provincial website for the public reporting of useful information about residential care facilities. The information should be updated regularly and organized in a way that makes it easy for seniors, their families and other members of the public to search for and compare facilities. The ministries have the website in operation by September 30, 2010.

42 OFFICE OF THE OMBUDSPERSON

Public Information and Reporting

Information available through this website should include but not be limited to:

Facility

- what legislation and regulation are applicable to the facility
- ownership
- whether accommodation and or bathroom facilities are private or shared
- whether there is specialized care available (for example, dementia care)
- the number of residents
- the date the facility was built
- the number of subsidized beds that are permanently funded and the number of subsidized beds that temporarily funded
- the number or percentage of residents who receive specialized care
- accreditation information
- whether the facility has a family council or a resident council
- what organization(s) or corporate entity(s) provides basic care, food, and housekeeping
- the point of contact at the facility for raising concerns or making complaints about any area of concern
- where concerns can be raised if it is felt the facility response is inadequate
- previous complaints about the facility and how they have been dealt with
- inspection reports and resolutions

Funding

- the per diem cost for individuals and an explanation of how this is determined
- items, services and activities included in the per diem charge and those available for an extra charge to residents, the amounts charged and how they are billed
- the per diem health authority funding
- whether there is a supporting charitable foundation for the facility and what type of support it provides

Staffing

 the direct care staffing levels for registered nurses, licensed practical nurses, and care aides

Public Information and Reporting

- the number of direct care hours provided per resident per day
- the number of direct care staff scheduled for each shift and their positions
- how access is provided to physicians and other health professionals such as chiropractors
- the number of occupational therapy, physical therapy and similar staff
- languages spoken by care providers

Quality of Care and Standards of Care

- sample menu and where food is prepared (such as whether food is prepared on-site in a facility kitchen, prepared elsewhere and reheated on-site, prepared elsewhere and delivered as ready-to-serve, or other method)
- social, recreational and other activities available on a regular basis to residents
- applicable personal care standards (such as the frequency of bathing, personal cleaning, and bathroom toileting policies)
- the facility's policy on the use of restraints
- standards for responding to call buttons
- policies concerning paid companions
- policies on accommodation of spouses
- policies concerning visitors, parking, pets, smoking, use of alcohol, and other similar information.

To the extent possible, this information should also be available in printed or other formats to make it accessible to all members of the public.

2(b) The Ministry of Health Services and the Ministry of Healthy Living and Sport review the evaluation model and information reporting that is to be implemented in Ontario after one year of its operation to evaluate whether there are further improvements that can be made to the British Columbia public information system.

44 OFFICE OF THE OMBUDSPERSON

Resident and Family Councils

"I go to a meeting once a month, but it is only a resident council meeting. The older people don't complain, as they are scared to. Scared they may get put out. They don't listen enough to senior's complaints." 32

To qualify for subsidized residential care, a person must be an adult, meet residency requirements and be unable to function independently because of chronic, health-related problems.³³ Many seniors are dependent on facility staff for assistance with basic needs, such as bathing, eating and going to the bathroom. They also rely on staff for companionship, which can be just as important to seniors as their food and activities. It is common for seniors to be uncomfortable complaining about their care, which makes them less likely to raise concerns about problems they experience with their care. Many residents are unable to advocate for themselves. Fortunately, some of these residents have family and friends who are able to advocate on their behalves. However, there are also residents in facilities who do not receive regular visitors and who do not have people who are prepared to advocate for their care. Residents and their families may find support for their concerns if the facility has an active resident or family council.

A resident council is a group of residents who meet in order to discuss their care.³⁴ Resident councils may differ from facility to facility in terms of their specific activities. For example, in addition to providing a forum to meet, resident councils may be involved in advocacy, event planning, and collaboration with facility managers on major decisions. Resident councils may work to improve the lives of residents by informing management of complaints and making recommendations for improvement.

Similarly, a family council is a forum in which family members and substitute decision-makers can meet regularly for support, raise concerns and work with residents and facility managers to improve the care and overall quality of life for residents. Like resident councils, family councils vary from facility to facility, with some having extremely active and well-established councils and others having no council at all.

³² Input received through the Office of the Ombudsperson's questionnaire on seniors' care.

³³ To meet the residency requirement, a person must have lived in British Columbia for the three months immediately prior to the application.

³⁴ Residents who are incapable of participating in councils may have a substitute decision-maker participate on their behalf.

Resident and Family Councils

The Current Situation

Regulations that Affect Resident and Family Councils

In British Columbia, legislated requirements regarding family and resident councils are minimal. Under the *Residential Care Regulation*, which came into force in October 2009, facility operators must meet with the council, where one exists, at least once annually. If no council is in place, facilities will be required to meet annually with residents in a group. In contrast, Ontario's *Long-Term Care Homes Act*, when it comes into force, will require operators in all facilities to "ensure that a Residents' Council is established in the home." 35

Facilities that are subject to the *Hospital Act* are not required to support either resident or family councils in any way and currently have no other legislated obligations regarding councils.

When the *Residents' Bill of Rights* comes into force in British Columbia, residents in facilities under both the *Community Care and Assisted Living Act* and the *Hospital Act* will have a right to establish and participate in a resident or family council to represent the interests of people in the facility. Residents will also have the right to have a family member or representative participate on a council on their behalf.³⁶

Resident and Family Councils Across the Province

In the course of our investigation, we asked each regional health authority for the following information:

- a list of all resident or family councils attached to residential care facilities in their region
- a copy of its policies on family and resident councils
- a description of its role in relation to resident or family councils
- a list of all council meetings health authority staff had been requested to attend in the past two years
- a list of all council meetings that health authority staff had attended in the past 24 months
- an explanation of how it ensures that the residential care facilities in its region are providing opportunities for family councils to meet with facility operators.

³⁵ Long-Term Care Homes Act, 2007, S.O. 2007, c. 8, s. 56(1). Ontario legislation, not yet in force.

³⁶ The *Health Statutes (Residents' Bill of Rights) Amendment Act, 2009* Schedule (Section 7), section 3(b) and (c).

46 OFFICE OF THE OMBUDSPERSON

Resident and Family Councils

Based on the responses to these questions, we concluded that there is wide variation among the regional health authorities regarding how they support and interact with resident and family councils. For example, one of the health authorities did not have a list of councils in its region. In the other four regional health authorities, it appeared that approximately two-thirds of residential care facilities had resident or family councils. Only one regional health authority had a policy about resident and family councils. In terms of meeting attendance, some health authorities had sent staff to more than a dozen meetings in the past 24 months, while in another region staff had only attended three.

What We Heard

We met with representatives of family councils during our investigation. We were told of cases in which family and resident councils had problems getting information from regional health authorities, and in which they did not perceive health authorities as supportive and encouraging of their activities. In one case, a number of family councils had come together to form a regional council, but when they invited other local family councils to join them, the health authority told them that this was not their role.

Members of family and resident councils and advocacy organizations told us that they believe resident and family councils should be encouraged to operate and to be effective. They told us that council structure needs to be flexible to enable variations between facilities, that council membership should be open to family members and other persons of importance to residents and that councils should be able to set their own agendas. They told us that facility staff and operators should participate only as invited guests at meetings. It was also suggested that there be designated liaisons to family councils in both the regional health authorities and residential care facilities.

Models in Other Jurisdictions

Ontario

Ontario currently operates similarly to British Columbia when it comes to family and resident councils. The Ontario *Nursing Homes Act* requires operators to assist with any request for the establishment of a resident council. However, the Ontario government recently passed the *Long-term Care Homes Act*. When in force, it will require operators to have resident and family councils that will be responsible for

- advising residents about their rights and obligations under the Act
- advising residents about the operator's rights and obligations under the Act

Resident and Family Councils

- attempting to resolve disputes between the operator and residents
- sponsoring and planning activities
- collaborating with community groups and volunteers
- advising the operator of concerns and recommendations³⁷
- reporting any concerns or recommendations to the director responsible for inspections in the government
- reviewing inspection reports, allocation of funding, financial statements and the operation of the long-term care home.

The new Act will require operators to respond to councils' concerns or recommendations within 10 days.

In addition, under the new Act, if there is no family council, the operator must advise residents' families or other "persons of importance" to residents of their right to establish a family council. The operator must also convene quarterly meetings to advise these groups of their right to establish a family council.

The Federal Nursing Home Reform Act in the United States

In the United States, the federal *Nursing Home Reform Act* and its regulations require nursing home operators to assist in the establishment of resident councils. The Act specifies that each facility should have a resident council that is elected annually by facility residents. The Act allows resident councils to advise facility administrators and directors in all policy matters and operational decisions that affect residents' care and life in facilities. Facility administrators are required to give proper consideration to councils' input. In addition, the Act states that each resident council should actively participate in choices about activities, food, living arrangements, personal care and other aspects of resident life. When requested by a resident, the Act allows a council to serve as an advocate in resolving grievances and ensuring residents' rights are observed.

The Act also guarantees the right to form and hold regular private meetings of resident and family councils. Facilities in the United States that are certified to receive Medicare and Medicaid funds must provide a meeting space for councils, cooperate with the council activities and respond to their concerns. Nursing facilities must appoint a staff advisor or liaison to the family council, but staff and administrators may attend council meetings only by invitation. Facilities must provide a designated staff person to provide assistance and

³⁷ The Act gives family councils powers similar to those of resident councils with the exception that resident councils can make recommendations to the facility, while family councils cannot.

Resident and Family Councils

respond to written requests from group meetings. The Act also requires facilities to listen to the views of residents and families about proposed policy and operational decisions and to act on their grievances and recommendations.

The Benefits of Resident and Family Councils

At their best, and when they are properly supported, councils give residents and their families a collective and therefore stronger voice in decisions about their own care. Councils provide a forum in which to share issues of concern and a formal procedure for bringing complaints forward. This increases the likelihood that residents and family members will voice their concerns. Resident and family councils also play an important role for seniors who do not have friends and family to speak for them. Members of resident and family councils are present at the facility and can observe the provision of care. They are well-positioned to advocate for individual improvements as well as systemic changes to care and how facilities operate.

Councils may also offer therapeutic and educational benefits. Moving into a care home, aging and being ill can all be difficult, and even traumatizing, experiences. Councils offer their members companionship, and support and advice from people who have had similar experiences. Some councils also bring in guest speakers to educate members about pertinent issues, such as depression, abuse and dementia. Further, councils are able to organize groups to work on projects, such as fundraising for a new van or other amenities. This allows them to take on larger tasks and lessens the likelihood that one person will be overburdened.

It is important for care facilities to have both resident and family councils because family members and residents have different perspectives, experiences and priorities. Having both types of councils increases the likelihood that creative solutions to problems will be discovered. Keeping resident and family councils separate ensures that the distinct and unique concerns of both are heard. For example, family members may be less likely to discuss some of the challenges they experience in caring for a loved one when those loved ones or other residents are present. Separate councils for residents also respect their autonomy.

Conclusion

Resident and family councils already play a constructive role in some seniors care facilities by bringing concerns and complaints forward, and allowing residents and families to have greater influence over the decisions made about their lives. However, they need support. With this support, there is potential for councils to fill an even greater role in addressing problems and empowering residents.

Resident and Family Councils

Resident and family councils are even more important to the many seniors who do not have family members, friends or advocates to assist them and speak on their behalf. For these seniors, active, well-supported councils are the best available mechanisms for ensuring their problems are resolved and their interests are represented. While residents and relatives cannot and should not be required to create or participate in councils, it is clear that these groups flourish when their importance is recognized, their input is sought and their concerns are addressed. Resident and family councils thrive when facility managers, regional health authorities, and in some cases ministry staff, are available to answer their questions and encourage their active operation. This has not always been the case.

The effectiveness of resident and family councils is currently limited by the lack of a provincial mechanism or process to provide them with encouragement and support and the absence of any coordinated response to systemic issues they raise. If the role of resident and family councils is expanded, it is likely to result in more issues and concerns being satisfactorily addressed by facilities without ever becoming formal complaints. The role of resident and family councils could be expanded to include

- advising operators about concerns and making recommendations for remedying them
- providing input to operators about policy matters and operational decisions
- advocating for residents in individual disputes
- reviewing inspection reports and other operational documents
- monitoring services to ensure residents' rights are respected.

In addition, in order for the councils to operate effectively, we believe that facilities and regional health authorities and the ministries should designate a staff person to assist and respond to councils. There should also be a requirement to respond within a specific time to concerns they raise. Two weeks can be a very long time for seniors and families dealing with concerns about the care provided in a facility. Currently a complaint made to Patient Care Quality Office can take up to 30 days for a response, and if the matter goes further to a Patient Care Quality Review Board, the board has 180 business days (about eight months) to respond.

Ombudsperson Finding

(3) Resident and family councils are important mechanisms for ensuring the well-being of residents in residential care facilities. The Ministry of Health Services and the Ministry of Healthy Living and Sport have not taken the necessary steps to ensure that resident and family councils are adequately supported.

Resident and Family Councils

Ombudsperson Recommendations

- 3(a) The Ministry of Health Services and the Ministry of Healthy Living and Sport take the necessary steps to entrench an expanded role for resident and family councils in legislation or regulation that applies to all residential care facilities in British Columbia. These changes should include a requirement to designate a liaison person at each facility and in each health authority to assist and respond to resident and family councils. These changes also should include timeframes for responding to resident and family councils. The ministries take these steps by March 31, 2010.
- 3(b) The Ministry of Health Services and the Ministry of Healthy Living and Sport provide guidelines for operators of all residential care facilities on the types of support they should offer resident and family councils. The ministries complete this by March 31, 2010.
- 3(c) The Ministry of Health Services and the Ministry of Healthy Living and Sport establish an ongoing position to promote and help develop resident and family councils, and to report publicly on those activities every year. This action to be taken by June 30, 2010.
- 3(d) The Ministry of Health Services and the Ministry of Healthy Living and Sport support the establishment and development of regional family council organizations.

Summary of Findings and Recommendations

Ombudsperson Findings

- (1) The Ministry of Health Services and the Ministry of Healthy Living and Sport have not adequately identified the province's commitment to care and the rights of seniors in residential care facilities.
- (2) The Ministry of Health Services and the Ministry of Healthy Living and Sport have not ensured that adequate information about residential care facilities is publicly available in an accessible format that allows seniors and their families to plan for and make informed decisions about residential care.
- (3) Resident and family councils are important mechanisms for ensuring the well-being of residents in residential care facilities. The Ministry of Health Services and the Ministry of Healthy Living and Sport have not taken the necessary steps to ensure that resident and family councils are adequately supported.

Ombudsperson Recommendations

- 1(a) The Ministry of Health Services and the Ministry of Healthy Living and Sport take the necessary steps to ensure that a commitment to care and the rights of seniors living in all residential care facilities are set out clearly in law by March 31, 2010.
- 1(b) The Ministry of Health Services and the Ministry of Healthy Living and Sport require all residential care facility operators to post the commitment and the rights at the entrance to the facility where it is easily visible to residents and visitors.
- 1(c) The Ministry of Health Services and the Ministry of Healthy Living and Sport develop a reliable and objective process to monitor and evaluate the degree to which residents' rights are respected.
- 1(d) The Ministry of Health Services and the Ministry of Healthy Living and Sport publicly report the results of this monitoring and evaluation annually, commencing in 2011.
- 2(a) The Ministry of Health Services and the Ministry of Healthy Living and Sport develop a single provincial website for the public reporting of useful information about residential care facilities. The information should be updated regularly and organized in a way that makes it easy for seniors, their families and other members of the public to search for and compare facilities. The ministries have the website in operation by September 30, 2010.

Summary of Findings and Recommendations

Information available through this website should include but not be limited to:

Facility

- what legislation and regulation are applicable to the facility
- ownership
- whether accommodation and or bathroom facilities are private or shared
- whether there is specialized care available (for example, dementia care)
- the number of residents
- the date the facility was built
- the number of subsidized beds that are permanently funded and the number of subsidized beds that temporarily funded
- the number or percentage of residents who receive specialized care
- accreditation information
- whether the facility has a family council or a resident council
- what organization(s) or corporate entity(s) provides basic care, food, and housekeeping
- the point of contact at the facility for raising concerns or making complaints about any area of concern
- where concerns can be raised if it is felt the facility response is inadequate
- previous complaints about the facility and how they have been dealt with
- inspection reports and resolutions

Funding

- the per diem cost for individuals and an explanation of how this is determined
- items, services and activities included in the per diem charge and those available for an extra charge to residents, the amounts charged and how they are billed
- the per diem health authority funding
- whether there is a supporting charitable foundation for the facility and what type of support it provides

Staffing

- the direct care staffing levels for registered nurses, licensed practical nurses, and care aides
- the number of direct care hours provided per resident per day

Summary of Findings and Recommendations

- the number of direct care staff scheduled for each shift and their positions
- how access is provided to physicians and other health professionals such as chiropractors
- the number of occupational therapy, physical therapy and similar staff
- languages spoken by care providers

Quality of Care and Standards of Care

- sample menu and where food is prepared (such as whether food is prepared on-site in a facility kitchen, prepared elsewhere and reheated on-site, prepared elsewhere and delivered as ready-to-serve, or other method)
- social, recreational and other activities available on a regular basis to residents
- applicable personal care standards (such as the frequency of bathing, personal cleaning, and bathroom toileting policies)
- the facility's policy on the use of restraints
- standards for responding to call buttons
- policies concerning paid companions
- policies on accommodation of spouses
- policies concerning visitors, parking, pets, smoking, use of alcohol, and other similar information.

To the extent possible, this information should also be available in printed or other formats to make it accessible to all members of the public.

- 2(b) The Ministry of Health Services and the Ministry of Healthy Living and Sport review the evaluation model and information reporting that is to be implemented in Ontario after one year of its operation to evaluate whether there are further improvements that can be made to the British Columbia public information system.
- 3(a) The Ministry of Health Services and the Ministry of Healthy Living and Sport take the necessary steps to entrench an expanded role for resident and family councils in legislation or regulation that applies to all residential care facilities in British Columbia. These changes should include a requirement to designate a liaison person at each facility and in each health authority to assist and respond to resident and family councils. These changes also should include timeframes for responding to resident and family councils. The ministries take these steps by March 31, 2010.

Summary of Findings and Recommendations

- 3(b) The Ministry of Health Services and the Ministry of Healthy Living and Sport provide guidelines for operators of all residential care facilities on the types of support they should offer resident and family councils. The ministries complete this by March 31, 2010.
- 3(c) The Ministry of Health Services and the Ministry of Healthy Living and Sport establish an ongoing position to promote and help develop resident and family councils, and to report publicly on those activities every year. This action to be taken by June 30, 2010.
- 3(d) The Ministry of Health Services and the Ministry of Healthy Living and Sport support the establishment and development of regional family council organizations.

Appendix A

Response of the Ministry of Health Services and the Ministry of Healthy Living and Sport



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Ms. Kim S. Carter Ombudsman Province of British Columbia 756 Fort St PO Box 9039, Stn Prov Govt Victoria BC V8W 9A5

Dear Ms. Carter:

Thank you for the opportunity to review and respond to the findings and recommendations contained in your first report on seniors' care in British Columbia. We have appreciated the opportunity to discuss your report with you, and have found your comments helpful in developing our joint response. Further to our response of October 24, 2009, and your October 30, 2009, letter to Mr. Allan Seckel, this letter will provide further clarification on the Ministries' response to your report. We would like to provide assurance that the Ministries are in substantial support of your recommendations, although we are proposing alternative approaches to achieve some of the recommendations by leveraging existing mechanisms and initiatives.

Our specific responses to your recommendations are outlined below:

1. Commitment to Care and Residents' Rights

Government fully supports the Ombudsman's observations that a clearly stated Resident Bill of Rights will make it easier for seniors and their families to understand the services and standards they are entitled to expect in residential care facilities.

In the August 25, 2009, Speech from the Throne, government made a commitment to introduce a Residents Bill of Rights to set out clearly the commitment to care and the rights of adults living in residential care facilities. Further, following extensive public consultation, a new Residential Care Regulation became effective October 1, 2009, replacing the former Adult Care Regulations. In addition, government has recently introduced amendments to the *Criminal Records Review Act*, which expands the requirements for criminal records check through the Criminal Record Review Agency to all persons who work with vulnerable adults, as well as children.

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¹ Government of British Columbia, Speech from the Throne, August 25, 2009 p. 10

Appendix A

Response of the Ministry of Health Services and the Ministry of Healthy Living and Sport

-2-

Ombudsman Recommendation

1 a) The Ministry of Health Services and the Ministry of Healthy Living and Sport take the necessary steps to ensure that a commitment to care and the rights of seniors living in all residential care facilities are set out clearly in law by March 31, 2010.

The Ministries accept this recommendation. Government passed Bill 17, *The Health Statutes (Resident Bill of Rights) Amendment Act 2009* on November 2, 2009. In developing this legislation, government considered whether application of resident rights should be limited to just seniors and made the decision to extend the rights to all adults in care.

Ombudsman Recommendation

1 b) The Ministry of Health Services and the Ministry of Healthy Living and Sport require all residential care facility operators to post the commitment and the rights at the entrance to the facility where it is easily visible to residents and visitors.

The Ministries accept this recommendation. To ensure that persons in care, family members, visitors and staff are aware of residents' rights, the *Resident Bill of Rights* requires facilities to post the rights in a prominent place in each facility.

Ombudsman Recommendation

1 c) The Ministry of Health Services and the Ministry of Healthy Living and Sport develop a reliable and objective process to monitor and evaluate the degree to which residents' rights are respected.

The Ministries accept the recommendation that there needs to be a reliable and objective process to monitor and evaluate the degree to which resident rights are respected. The Ministries are committed to supporting timely resolution of concerns and will reflect this in policy. Where a resident or family member is not able to resolve concerns with the facility, they may be brought to either the Medical Health Officer (MHO) or the Patient Care Quality Office (PCQO) in the health authority. Both have the authority to address concerns, and to raise issues through senior leadership staff in the health authority, and the Ministries.

Complaints received by Patient Care Quality Offices and Review Boards are tracked and reported regularly to the Ministry of Health Services. Both Patient Care Quality Offices and Medical Health Officers may refer matters to each other as appropriate to ensure timely response.

The Ministry of Healthy Living and Sport will require community care licensing staff to monitor facility compliance with the Bill of Rights and report their findings to the Ministry on a regular basis, by March 31, 2010.

Appendix A

Response of the Ministry of Health Services and the Ministry of Healthy Living and Sport

- 3 -

Ombudsman Recommendation

1 d) The Ministry of Health Services and the Ministry of Healthy Living and Sport publicly report the results of this monitoring and evaluation annually commencing in 2011.

The Ministries accept this recommendation and acknowledge that reporting the results of monitoring and evaluation should be shared with the public. Both Ministries will evaluate a fiscally responsible approach to implementing this recommendation, by improving and expanding the effectiveness of existing structures by June 2011.

2. Public Information and Reporting

The Ministries agree that ready access to current and reliable information for seniors and their families is important and that there are opportunities to improve this across the province. As you are aware, both Ministries have been working collaboratively in response to the Premier's Council on Aging report entitled "Aging Well in BC", which made specific recommendations for coordinated and accessible information for seniors.²

Ombudsman Recommendation

2 a) The Ministry of Health Services and the Ministry of Healthy Living and Sport develop a single provincial website for the public reporting of useful information about residential care facilities. The information should be updated regularly and organized in a way that makes it easy for the seniors, their families and other members of the public to search for and compare facilities. The ministries have the website in operation by September 30, 2010.

The Ministries accept the intent of this recommendation. The Ministries will build on and leverage current structures to improve access to information to support seniors in living independently, and to understand the options available to them for care and support. The Seniors' Portal, currently under development by the Seniors' Healthy Living Secretariat, will serve very well as a primary point of contact for public information about services for seniors. In addition, we will work to improve information available through HealthLink, BC's health resources website, which is further supported through the 8-1-1 telephone service, available 24 hours a day in several languages.

The Ministries will commit to working through the Seniors' Healthy Living Secretariat, HealthLink BC and the health authorities to improve the quality and consistency of information available regarding health care services across the province, including residential care facilities. Specific information items identified by the Ombudsman will be considered, subject to review for legal and privacy requirements. Components of this work have already begun, and will be completed by September 2010.

...4

² www.hls.gov.bc.ca/seniors/council/docs/Aging Well in BC.pdf. See recommendation 8 "Getting information out."

Appendix A

Response of the Ministry of Health Services and the Ministry of Healthy Living and Sport

- 4 -

Ombudsman Recommendation

2 b) The Ministry of Health Services and the Ministry of Healthy Living and Sport review the evaluation model and information reporting that is to be implemented in Ontario after one year of its operation to evaluate whether there are further improvements that can be made to the British Columbia public information system.

The Ministries accept this recommendation, and will review information sites in Ontario and other Canadian and international jurisdictions to evaluate and improve public information available in BC.

3. Resident and Family Councils

The Ministries agree that resident and family councils are important, both for promoting the well-being of residents and for providing support to family members in their ongoing role as caregiver for their loved ones. The Ministries further agree that it is vital that family members and staff establish a mutually respectful relationship, for the benefit of persons in care. This is consistent with provisions in the *Resident Bill of Rights* to establish and participate in a resident or family council, and to have a family member or representative participate on a resident or family council on behalf of the resident, if they choose.

The Residential Care Regulation also contains expanded provisions regarding resident and family councils, intended to support this goal.

Ombudsman Recommendation

3 a) The Ministry of Health Services and the Ministry of Healthy Living and Sport take the necessary steps to entrench an expanded role for resident and family councils in legislation or regulation that applies to all residential care facilities in British Columbia. These changes should include a requirement to designate a liaison person at each facility and in each health authority to assist and respond to resident and family councils. These changes also should include timeframes for responding to resident and family councils. The ministries take these steps by March 31, 2010.

The Ministries accept the recommendation, and as noted above have entrenched resident and family councils in both legislation (Bill of Rights) and regulation (Residential Care Regulation). Additional recommendations will be implemented through policy.

The Ministries will work with the health authorities to provide increased education and support to resident and family councils, and to recommend a point of contact in each facility for family members. Revised policies will be introduced by March 31, 2010.

Appendix A

Response of the Ministry of Health Services and the Ministry of Healthy Living and Sport

- 5 -

Ombudsman Recommendation

3 b) The Ministry of Health Services and the Ministry of Healthy Living and Sport provide guidelines for operators of all residential care facilities on the types of support they should offer resident and family councils. The ministries complete this by December 31, 2009.

The Ministries accept this recommendation. Guidelines will be provided for operators of residential care facilities, including identification of the individual to contact if they have a concern. The Ministries anticipate that they will have these guidelines completed by March 31, 2010.

Ombudsman Recommendation

3 c) The Ministry of Health Services and the Ministry of Healthy Living and Sport establish an ongoing position to promote and help develop resident and family councils and to report publicly on those activities every year. This action to be taken by June 30, 2010.

The Ministries accept the intent of this recommendation. The Ministries will work with health authorities to further promote resident and family councils, as an important component of a commitment to support family caregivers in all settings. This coincides with current initiatives to the patient as a partner in care, and to provide improved tools and supports to caregivers through both primary health care and home and community care initiatives.

Ombudsman Recommendation

3 d) The Ministry of Health Services and the Ministry of Healthy Living and Sport support the establishment and development of regional family council organizations.

The Ministries accept the recommendation, and will require through policy that health authorities provide opportunities for family council members to participate regionally.

Thank you again for the opportunity to respond. We appreciate the ongoing dialogue with you on these issues and look forward to receiving your full report in the near future.

Sincerely,

Kevin Falcon
Minister of Health Services

Sincerely,

Ida Chong, FCGA

Minister of Healthy Living and Sport

Appendix B Excerpt from the Health Statutes (Residents' Bill of Rights) Amendment Act, 2009

2009 Legislative Session: 1st Session, 39th Parliament

Third Reading

Bill 17 — 2009

Health Statutes (Residents' Bill of Rights) Amendment Act, 2009

Schedule

(Section 7)

Rights of adult persons in care

1 The rights of an adult person in care are as set out in clauses 1 to 5 of this section.

Commitment to care

- 1. An adult person in care has the right to a care plan developed
 - (a) specifically for him or her, and
 - (b) on the basis of his or her unique abilities, physical, social and emotional needs, and cultural and spiritual preferences.

Rights to health, safety and dignity

- 2. An adult person in care has the right to the protection and promotion of his or her health, safety and dignity, including a right to all of the following:
 - (a) to be treated in a manner, and to live in an environment, that promotes his or her health, safety and dignity;
 - (b) to be protected from abuse and neglect;
 - (c) to have his or her lifestyle and choices respected and supported, and to pursue social, cultural, religious, spiritual and other interests;
 - (d) to have his or her personal privacy respected, including in relation to his or her records, bedroom, belongings and storage spaces;
 - (e) to receive visitors and to communicate with visitors in private;
 - (f) to keep and display personal possessions, pictures and furnishings in his or her bedroom.

Rights to participation and freedom of expression

- 3. An adult person in care has the right to participate in his or her own care and to freely express his or her views, including a right to all of the following:
 - (a) to participate in the development and implementation of his or her care plan;

Appendix B Excerpt from the Health Statutes (Residents' Bill of Rights) Amendment Act, 2009

(b) to establish and participate in a resident or family council to represent the interests of persons in care;

- (c) to have his or her family or representative participate on a resident or family council on their own behalf;
- (d) to have access to a fair and effective process to express concerns, make complaints or resolve disputes within the facility;
- (e) to be informed as to how to make a complaint to an authority outside the facility;
- (f) to have his or her family or representative exercise the rights under this clause on his or her behalf.

Rights to transparency and accountability

- 4. An adult person in care has the right to transparency and accountability, including a right to all of the following:
 - (a) to have ready access to copies of all laws, rules and policies affecting a service provided to him or her;
 - (b) to have ready access to a copy of the most recent routine inspection record made under the Act;
 - (c) to be informed in advance of all charges, fees and other amounts that he or she must pay for accommodation and services received through the facility;
 - (d) if any part of the cost of accommodation or services is prepaid, to receive at the time of prepayment a written statement setting out the terms and conditions under which a refund may be made;
 - (e) to have his or her family or representative informed of the matters described in this clause.

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