LAW REFORM COMMISSION OF SASKATCHEWAN

Consultation Paper:
Civil Rights in Saskatchewan Long-term Care Facilities

AUGUST 2010

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1. Introduction

1.1 Civil rights in long-term care

Elderly people and others in long-term care[1] are entitled to the same respect as other citizens. As the Canadian Network for the Prevention of Elder Abuse observes, "residents of nursing homes and other institutional settings have all the rights of other adults. They do not leave their rights at the front door." The Network also observes that "many residents are unaware that they have the same rights as people in the community, and should not have to experience abuse, neglect or violation of their rights."[2]

Violation of civil rights of long-term care residents is a species of abuse. A widely accepted definition of abuse of the elderly characterizes "violation of civil/human rights" as:

> Denial of a senior's fundamental rights (as set out in legislation, the Charter of Human Rights and Freedoms, common law): e.g., withholding information, denial of privacy, denial of visitors, restriction of liberty, or mail censorship.[3]

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[1]In Saskatchewan, long-term care facilities include "special care homes" operated by Regional Health Authorities, and privately operated "personal care homes." See below for a description of these institutions.

[2]Canadian Network for the Prevention of Elder Abuse, *Abuse in institutions*, n.d.

[3] *Connecting: A Curriculum Guide on the Abuse of Seniors*, British Columbia Coalition to Eliminate the Abuse of Seniors, April, 1996. The other forms of abuse included in the definition are physical abuse, financial abuse and exploitation, sexual abuse, neglect, and medication abuse.

Violations of civil rights may range from life threatening abuse to simple disrespect for the autonomy and privacy of residents, and obviously overlaps with other forms of institutional abuse. Some violations of rights, such as inappropriate use of physical restraints, would be recognized as abusive by almost everyone. Others are perhaps more subtle examples of abuse, but still impact on the quality of life of the victim. For example, competent residents may be denied to right to leave the facility to visit a nearby coffee shop. The facility may adopt such a policy out of concern for the safety of residents, but it is nevertheless a clear violation of a competent adult's legally protected right to autonomy.

While most elders are mentally competent, there is a tendency to treat older people, particularly if they have been admitted to long-term care, as less than fully responsible and competent. There is a presumption in law that an adult is competent unless found to be incompetent by a court or certified incompetent by examining physicians.[4] Even if a resident is incompetent, the right to be respected as an individual is not extinguished. Both law makers and care givers increasingly recognize that the wishes and autonomy of adults with diminished capacity should be respected as much as the circumstances permit.[5] There is perhaps an inevitable

[4]See *The Adult Guardianship and Co-decision-making Act*, c. A-5.3 and *The Mentally Disordered Persons Act*, c. M-14.

[5]For example, *The Adult Guardianship and Co-decision-making Act* provides:

3 This Act shall be interpreted and administered in accordance with the following principles:

(a) adults are entitled to have their best interests given paramount consideration;

(b) adults are entitled to be presumed to have capacity, unless the contrary is demonstrated;

(c) adults are entitled to choose the manner in which they live and to accept or refuse support, assistance or protection, as long as they do not harm themselves or others and have the capacity to make decisions about those matters;

(d) adults are entitled to receive the most effective, but the least restrictive

tension between paternalism and autonomy in care-giving institutions. This may make it more difficult to recognize violations of civil rights than other forms of abuse. The Ontario Advocacy Centre for the Elderly (ACE) observes that "in institutional settings, some forms of abuse are not always obvious. Subtle emotional harms may occur such as treating older people like children (infantilization) and disregarding their wishes."[6]

1.2 The scope of this consultation paper

There is little doubt that abuse is a potential problem in long-term care facilities. Studies across Canada have shown that abuse occurs, and that active measures are necessary to control it.[7] Saskatchewan long-term care facilities are aware of abuse

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and intrusive, form of support, assistance or protection, when they are unable to care for themselves or their estates;
(e) adults who have difficulty communicating because of physical or mental disabilities are entitled to communicate by any means that enables them to be understood;
(f) adults are entitled to be informed about and, to the best of their ability, participate in, decisions affecting them.

[6]Joanne Preston and Judith Wahl, *Abuse Education, Prevention and Response: A Community Training Manual for those who want to address the Issue of the Abuse of Older Adults in their Community by,* 3rd ed., Advocacy Centre for the Elderly (ACE), December 2002. As ACE suggests, these attitudes can become ingrained in institutional culture, becoming "systemic abuse," described as "practices that take away a person's independence and dignity. Systemic abuse happens in settings where other people are making decisions for the person who has a disability."

[7]Elder abuse generally: Elizabeth Podnieks, Karl Pillemer, Thomas Shillington & Alan Frizzel, *National Survey on Abuse of the Elderly in Canada: The Ryerson Study*, Ryerson Polytechnical Institute; Toronto; 1990. In Saskatchewan: Saskatoon Council on Aging Older Adult Abuse Task Force presentation, *National Perspectives on Elder Abuse: Join the Conversation,* ONPEA Conference, November 3-4, 2009 Toronto, Ontario. Abuse in long-term care: C. Spencer, *Abuse and Neglect of Older Adults in Institutional Settings*, Health Canada, 1994. A study conducted by the College of Nurses of Ontario is particularly interesting in this context. It found that 43% of incidents of abuse reported by Ontario community

issues. Almost all have protocols to deal with abuse, and most have educational programs to familiarize staff with the problem of abuse.[8] It is not the purpose of this paper to review these efforts in detail. The focus is, rather, on violations of the rights of residents, particularly when they do not involve physical abuse, and particularly when they may not be effectively addressed by existing protocols designed to deal with more blatant forms of abuse.

The Law Reform Commission became interested in this topic after participation in the Canadian Conference on Elder Law in 2006. ACE lawyer Judith Wahl spoke to the Conference about her experience dealing with violations of civil rights in Ontario long-term care facilities. She suggested that this form of abuse may too easily may "fall through the cracks." The scope of the problem in Ontario was recognized only because of the ACE's active role as an advocate for individual residents. Discussion among Saskatchewan delegates revealed that little is known about the problem in Saskatchewan. The Commission subsequently undertook to investigate issues of civil rights in Saskatchewan long-term care facilities.

The Commission determined that the first step should be an assessment of the extent of violations of civil rights in Saskatchewan facilities: Is there a problem in Saskatchewan? To answer this question, the Commission engaged Professor Doug Surtees of the University of Saskatchewan College of Law to conduct an empirical study of the status of civil rights in Saskatchewan special care homes.[9] The next

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health care nurses were "verbal." Many violations of civil rights would fall nto this category: *Speak out to Stop Abuse*, College of Nurses of Ontario, 1997.

[8]For example, many Saskatchewan special care homes use the training provided by The Eden Alternative: "The Eden Alternative is an international not-for-profit organization dedicated to transforming care environments into habitats for human beings that promote quality of life for all involved. It is a powerful tool for inspiring well-being for Elders and those who collaborate with them as Care Partners" (Eden Alternate web site http://www.edenalt.org/).

[9]This study did not include personal care homes, but the results can likely be extrapolated to

section of this paper sets out the findings of the study.

Professor Surtees reports that "The stories related [to him in the interviews he conducted] make it clear that many professionals and family members are gravely concerned over aspects of life in special care homes in Saskatchewan." There is sufficient evidence of violations of civil rights to proceed to the second phase of the project. The final section of this paper examines initiatives in other jurisdictions that address the civil rights of residents in long-term care facilities, and discusses them as options that might be adopted in Saskatchewan.

The purpose of this paper is to encourage discussion, and to solicit input from members of the community. The Commission hopes that respondents will assist it in clarifying civil rights concerns in long-term care, and help it to articulate appropriate steps which should be taken to ensure protection of civil rights of residents.

WE WELCOME YOUR COMMENTS

1.3 Long-term care facilities in Saskatchewan

There are two types of long-term care facilities in Saskatchewan: Special care homes, and personal care homes. Special care homes are public institutions, operated by the Regional Health Authorities. Personal care homes are privately operated facilities. They are usually smaller, and may not provide as wide a range of levels of care as special care homes.

At present, there are 128 special care homes in the province, providing room for 8522

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them.

residents. Although admission to special care homes is based on need rather than age, most residents are elderly, and the proportion of older residents is increasing.

The Department of Health describes special care homes in these terms:

> [A] special-care home is a facility that provides institutional long term care services to meet the needs of individuals usually having heavy care needs, that cannot appropriately be met in the community through home/community based services. Special-care homes are sometimes referred to as nursing homes.
>
> Special-care homes may also provide support to family care providers through respite care and adult day programs.
>
> Special care homes are designated by the Minister under *The Regional Health Services Act*[10]. Regional Health Authorities may operate a special-care home directly or through an affiliation contract.[11]

An individual may be admitted to a special care home for short term respite care during a period of convalescence, or as a permanent resident. Regional Health Authority assessment units work to find appropriate accommodation based on need. Costs to the resident are determined under *The Regional Health Services Act*, and vary according to the resident's income. The level of care provided to permanent residents depends on need:

> Supervisory Care provides guidance or supervision of a resident's daily living.
>
> Limited Personal Care provides residents who can get around on their own with

[10]*The Regional Health Services Act*, S.S. 2002, c. R-8.2

[11]Saskatchewan Department of Health, http://www.health.gov.sk.ca/special-care-homes/

assistance with things such as personal hygiene, dressing and grooming.

Intensive Personal Care provides residents who are bedridden assistance with things such as personal hygiene, dressing and grooming.

Limited Nursing Care goes beyond personal care services to include things such as bathing, feeding and administering medications and minor treatments.

Long-term Care provides prolonged nursing and personal care. Care is under continuing medical supervision and nursing care is under continuing nursing supervision.[12]

Although the services provided by personal care homes are similar to those available in special care homes, they are operated and regulated differently. They are described by the Department of Health in these terms:

Personal care homes, although licensed and monitored by Saskatchewan Health, are privately owned and operated. Personal Care Homes must operate in accordance with:

* The Personal Care Homes Act[13];
* The Personal Care Home Regulations; and
* The Licensees' Handbook. . . .

The type of care provided in personal care homes varies from home to home. While personal care homes usually accommodate individuals with lighter care needs, some personal care homes do provide care to persons with heavier care needs (such as palliative care).

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[12]Public Legal Education Association of Saskatchewan (PLEA), *Special-care Homes,* January 1, 2007.

[13]*The Personal Care Homes Act,* S.S. 1989-90, c. P-6.01

In either case, the personal care home is responsible for providing safe and adequate care to each resident in the home. This includes accessing the services of a health care professional (such as nurses and doctors) when required.[14]

[14]Saskatchewan Department of Health, http://www.health.gov.sk.ca/personal-care-homes

2. Civil rights in special care homes: An empirical study

2.1 Background

The Law Reform Commission of Saskatchewan is interested in discovering the extent to which the civil rights of residents of special care homes in Saskatchewan are being respected. To this end the Law Reform Commission funded Professor Doug Surtees to gather and analyze data.

The research plan was developed after consultation with public legal education and information professionals and members of the academic and professional communities. The plan was designed to allow those familiar with individuals in special care homes to share their stories. It was hoped that the resultant stories, while not constituting a statistically representative sample, would provide a broadly based sampling of concerns of residents, their family and friends as well as of staff or long-term care facilities. An initial description of the methodology was presented for review and feedback at a 2007 national conference of public legal education and information providers, and at the third annual Canadian Conference on Elder Law (2007) in Vancouver.

The Behavioural Research Ethics Board of the University of Saskatchewan granted ethical approval for this research project.

2.2. Methodology

Data was gathered in two ways:

1. By speaking to friends and family members of residents of long-term care facilities, and
2. By sending a survey questionnaire to long-term care facilities (see Appendix).

The researcher made the project known by informing members of the public legal education and information community (by speaking at their 2007 annual conference), members of the bar (by posting a notice on the web page of the Law Society of Saskatchewan), members of the Saskatoon Council on Ageing and members of FACE, an association of families advocating for caring environments for individuals in care.

The research plan was not designed to capture statistically significant data. Rather, the design was intended to facilitate the development of a narrative by listening to the stories of those close to the residents. The research plan did not include speaking directly with residents. Leaving residents out of the interview process was a deliberate choice aimed at minimizing the any possible risk of retaliation against residents for their comments or perceived comments. Excluding residents of special care homes from the group of people being interviewed also streamlined the ethical approval process.

2.2.1 Interviews

In order to raise awareness of this project and in order to solicit volunteers to be interviewed, the researcher enlisted the support of the Public Guardian and Trustee Office (PGT) and the Public Legal Education Association of Saskatchewan (PLEA). The PGT has employees who routinely deal with clients in long-term care facilities throughout Saskatchewan. PLEA deals with hundreds of telephone callers per year, and indicated they would, where appropriate, advise callers about the project and provide the researcher's contact information. In addition, the researcher gave a presentation regarding the project to the Saskatchewan Council on Ageing and to FACES. The researcher discussed the project at a CBA conference session dealing with elder law, as well as at the previously mentioned national elder law conference and national Public Legal Education conference. The Law Society of Saskatchewan posted information regarding the project on its web site beginning in March 2008. Finally, as previously mentioned, information about the project was mailed to 154 long-term care facilities.

Following the revised format, the researcher was able to meet with a total of 23 individuals. Even this relatively low number of interviewees was only achieved through follow-up phone calls and email as reminders to individuals who had indicated they wished to speak to the researcher. Many people who indicated they had a story to share did not follow through. This may be because it was difficult for family members of residents to share their stories. Several indicated that although they appreciated the opportunity to tell their loved one's story, it was still difficult to go through the process of telling it.

Of the 23 interviewees, 13 shared stories based upon what they learned in a professional capacity. That is to say they were acting in a professional capacity when they observed the incidents which were related in their stories. Often these individuals shared numerous stories involving many incidents and many residents.

The remaining 10 individuals shared stories about a loved one in a Saskatchewan long-term care facility. At least three of these individuals were or had been professionally connected to long-term care facilities, but the stories they shared were personal. Recounting the stories was clearly difficult for many of the story tellers. At least five specifically volunteered that the interview was a difficult experience.

2.2.2 Special Care Home Survey

The researcher developed a questionnaire to solicit basic information from special care homes. The questionnaire was designed to fit on a single page and so that it could be completed in a matter of a few minutes. The questionnaire was an attempt to involve special care homes, to advise them of the research project and to gather their perceptions or a number of matters which it was anticipated would be matters of interest to family members of residence. Although not feasible in the time frame allowed for the project, it would have been helpful to conduct interviews with family members in advance of developing the survey questionnaire. However,

mailing the survey questionnaires in advance of the interviews did have the advantage of not creating a situation where special care homes heard about the interviews and felt as if they were left out, or an afterthought. Feedback on the survey questions was gathered from public legal education and information providers prior to the survey being mailed out.

A package of information was mailed out to each of the 154 special care homes in Saskatchewan. The list of special care homes was compiled from information found in the Saskatchewan Gazette. Each package consisted of a letter containing a description of the project, the researcher's name, telephone and fax numbers, address, and email; a consent form; a questionnaire; and a stamped envelope addressed to the researcher to assist with returns. Twenty-seven completed questionnaires were returned. This represents a 17.5% return rate.

In one case the long-term care employee responsible for completing the questionnaire contacted the researcher to set up an appointment to be interviewed. During the interview this individual shared many valuable stories involving respect for civil rights with long-term care homes.

2.3 Survey Questionnaire Results

Responses to survey questions are discussed below. Since the survey was not designed to be statistically valid, it is not possible to extrapolate findings to special care homes throughout the province. It is possible, however, to make some observations regarding the survey. Administrators and staff of special care homes are aware that abuse is a problem, and conscious that residents have rights which ought to be respected. However, the responses to the questionnaire lacked the sense of urgency that characterized the responses of interviewees. The gulf between the perceptions of special care homes and the families of residents may itself be a significant problem.

2.3.1 Right to vote

1. Are residents permitted to vote in: (please check all that apply)

❑ **Federal elections** ❑ **Provincial elections** ❑ **Municipal elections**

If so, do staff provide any assistance to residents to help them vote?

❑ **Yes, we ask if they require assistance** ❑ **Yes, but only if residents ask for help** ❑ **No**

There have been reports of incidents in recent elections in which the voting rights of long-term care residents have not been respected. Since residents otherwise qualified to vote do not lose this right when they enter care, respect for the right to vote is likely a good indicator of attitudes toward residents' autonomy.

All respondents indicated residents were entitled to vote in federal and provincial elections. Eight respondents left the municipal election box blank. One of these indicated in a written comment that residents would be permitted to vote in a municipal election and another indicated the responder was unsure. Given the unanimous answers with respect to federal and provincial elections, the blanks likely mean the responder was unsure. It would not be logical to infer a prohibition on voting in municipal elections while recognizing a right to vote in federal and provincial elections. Eight special care homes indicated they will not provide any assistance to residents to help them vote. One responder left the question blank asking if the home provides assistance, and 18 indicated they do provide some assistance. Of course failure to provide required assistance (presumably in getting the resident to the polling station, as Elections Canada provides needed assistance from that point on) could effectively take away a resident's right to vote.

2.3.2 Staff education concerning civil rights

2. Think of the staff seminars available to staff at your institution (either on-site or off-site, such as at a

conference). Have any of these seminars been concerned with increasing the respect for civil rights of residents? ❑ **Yes** ❑ **No**

If "Yes", please list the topics and indicate approximately how many sessions were held:

The second question asked if staff seminars (either on-site or off-site such as a conference) have been concerned with increasing respect for the civil rights of residents. Nine special care homes indicated 'yes' and 18 indicated 'no'. One of the 'no' responders indicated that they do have ongoing discussions at staff meetings regarding residents' right to choice and that literature on this topic is distributed to staff.

The respondents who indicated 'yes' identified the following seminars: Provincial long-term care conference, ongoing Eden Alternative training, and Dignity For All sessions on particular legislation and privacy/confidentiality matters and Residents' rights.

There appears to be a clear divide among special care homes when it comes to providing staff seminars aimed at increasing respect for civil rights of residents. One 'no' respondent specifically cited the lack of affordable resources in this area. Another indicated that although all workshops in the province were posted so that staff would have the opportunity to attend, few did.

It appears that a significant number of special care homes are staffed by people who do not have the opportunity to attend educational seminars aimed at increasing the respect for civil rights of residents. A reasonable assumption is that increased knowledge of civil rights will result in increased respect for civil rights.

2.3.3 Residents' tobacco and alcohol use

3. Are residents allowed to smoke?

❑ **Yes** ❑ **Yes, provided they do not need assistance** ❑ **No**

4. Are residents allowed to drink alcohol?

❑ **Yes** ❑ **Yes, provided they do not need assistance** ❑ **No**

Because the use of alcohol and tobacco can impact the well being of other residents, restrictions may be appropriate. However, the facility is also the home of its residents. In other jurisdictions, smoking and drinking have been contentious issues when residents believe that there is not reasonable accommodation of their lifestyle choices. Judith Wahl of the Ontario Advocacy Centre for the Elderly suggests that institutional willingness to accommodate is often an indicator of attitudes toward residents' rights.

All respondents except one indicated that residents are allowed to smoke. Three of the positive responses qualified their statements by indicating that the resident had to be off health region property, as a 'no smoking on health region property' policy was in effect. The negative respondent did not indicate whether or not they considered off-property smoking.

All respondents indicated residents were permitted to drink alcohol.

2.3.3 Residents' councils

5. Does your facility have a resident's council?

❑ **Yes, and it is active** ❑ **Yes, but it is not active** ❑ **No**

An active residents' organization may indicate an environment in which residents are consulted and respected. Nineteen respondents indicated they have an active Residents' Council. One respondent indicated they had an inactive Residents' Council but hope for improvements to it soon. One respondent indicated that the home had a brand-new Residents' Council, and six respondents indicated they have no Residents' Council. Interestingly, four of the six respondents who indicated they do not have a Residents' Council, also indicated that they do have staff seminars concerned with increasing respect for civil rights of residents. Looked at a different way, 4/9 of respondents who indicated the availability of staff seminars on residents' rights, also

indicated that they do not have a Residents' Council.

2.3.4 Residents' Bill of Rights

6. Does your facility have a document such as a 'Resident's Bill of Rights'?

- ❑ **Yes, and we take steps to make residents and their families aware of it**
- ❑ **Yes, and we take steps to make residents aware of it**
- ❑ **Yes, but we do not take steps to make residents or their families aware of it**
- ❑ **No**

A "Bill of Rights" or other statement setting out the basic rights of residents has been suggested as a means to encourage respect for the rights of residents, and some jurisdictions have adopted such a document by legislation. [15]

One respondent did not answer the question asking if they have a Residents' Bill of Rights. One other indicated that they are only now in the process of formulating one. Of the remaining 25 respondents, 18 indicate they do have one and take steps to make residents and families aware of it. One indicated they post a notice at the front door. One other indicated they include the information in the admission package. One respondent indicated they take no steps to make residents or families aware of the Residents' Bill of Rights. The remaining four indicated they do not have a Residents' Bill of Rights. Of these four, one had indicated that residents are not allowed to smoke, two had indicated that staff will not provide assistance to residents to help them to vote and two indicated they do not have a Residents' Council. It would seem that the lack of a formal recognition of residents' rights (in a Bill of Rights) is correlated to a lack of civil rights as compared to other special care homes which completed the questionnaire.

[15] See below

2.3.5 Use of incontinent products

7. Do you have a policy limiting either the number of incontinent products used by a resident, or the time a resident's incontinent product may be changed? ❑ **Yes** ❑ **No**

If "Yes", please describe the policy or attach it

The way in which incontinent products, such adult diapers, are used in a home may be an indicator of the level of respect accorded to residents, and has been flagged as an issue in other studies. During the interviews conducted for this study, Many family members' reported the perception is that their loved one does not have their incontinence product changed sufficiently often. However, this does not appear to be an issue recognized by the facilities that responded to the questionnaire. No respondent indicated they have a policy limiting the number of incontinent products used by a resident, or the times at which those incontinent products may be changed.

2.3.6 Privacy

8. Do you have a policy regarding privacy for residents while they are being bathed or undressed?

❑ **Yes** ❑ **No**

If "Yes", please describe the policy or attach it:

The final question asked special care homes if they had a policy regarding privacy for residents while they are being bathed or undressed. Eleven answered 'yes', one left the boxes unchecked but explained what their policy was, and fifteen answered 'no'. Of the fifteen who answered 'no', however, nine went on to indicate a policy or practice in place to protect the residents' privacy and dignity. Presumably this question was not clear enough as a significant number of the 'no' responses seem that they should have actually been 'yes' responses. No

conclusion can be drawn from the six special care homes which indicated 'no policy' without an explanation. At least 21 of 27 respondents appear satisfied that they have measures in place to protect the privacy of residents while they are being bathed or dressed. It may be that the remaining six misunderstood the question as others appear to have.

2.4 Interviews

Professor Surtees observed that "there was a tremendous similarity amongst the stories [interviewees] told me, and the way they told those stories. Participants, especially, but not only, family members, found it difficult to tell the stories – as if telling the stories meant reliving difficult personal events. Yet participants seemed genuinely glad to have the opportunity to share their story with me, even though they understood that I did not work for or report to the health care system and therefore I am not in a position to implement any change."

In the summary below, interviewees' comments have been grouped into three large themes. Each of these themes came up repeatedly in interviews. Although the specific examples differed from person to person, the incidents people reported generally fit into the themes of respect, staff/bed Shortages, and workplace-home Conflict. Although the stories told by interviewees cover much more than civil rights as defined in this paper, the issues they raise all reflect on the question of whether the environment in special care homes appropriately fosters respect for the rights of residents as autonomous adults. The interviews include examples of conflict beginning with discussions surrounding the individual's placement in a special care home, continuing through virtually all aspects of life in a special care home, even to the resident's memorial service following their death.

2.4.1 Respect

"[It's as if] they are not people anymore – just something which needs to be cared for."

---- Interviewee with parent in care

This is without a doubt the broadest theme. It encompasses the widest range of incidents of any of the four themes, and perhaps connects most directly with civil rights concerns. The interviews suggest that lack of respect for residents is widespread in special care homes. Many interviewees made a point of saying that many of the staff are wonderful, caring people. Many spoke of particular individuals and even entire special care homes where the care they received was wonderful and the staff treated all residents with respect. But unfortunately, this was usually done to contrast what was seen as poor care, and a lack of respect by others.

The respect accorded to residents intimately reflects institutional culture. Some interviewees spoke of individuals who, when they began working at the special care home. were like a breath of fresh air, but after a while, began to change. One interviewee suggested that "nice people come in. After a while they are indoctrinated. They have to play both sides."

The prairies were built on their backs. We don't respect our elders.

— Interviewee

Some interviewees perceived the language used by staff and administrators to be dehumanizing. One staff member told me that the common term for a resident who is eating is "feeder." The term for a resident who wanders is "wanderer." This staff member indicated that staff who used these terms were often individuals who cared deeply about the residents, and who would speak to the need to treat residents with respect in staff meetings. Immediately after however, they would use language like "feeders" and "wanderers." If good-hearted staff can identify the need to treat residents with respect, but can leave a staff meeting and refer to some as "feeders" and some as "wanderers," there must be something else at play. That "something else" is institutional culture.

Institutional culture would also seem to play a role in the staff practice of removing residents' hats at meal time, and correcting residents' manners by saying "thank you" if a resident

does not do so when food is served. This type of disrespectful language is really an example of treating adults like children. No server in a restaurant would do either of these things. In fact, no one is likely to do it to anyone else, save for children who are in their care.

A sense that there is a lack of respect can begin as early as the placement process. Although residents were only asked about their experiences as residents of special care homes, two volunteered placement stories. The "first available bed" policy was seen as resulting in additional stress on families who are only beginning to cope with the sometimes sudden incapacity of a loved one. One individual related the story of their family "fighting" to keep a parent from being placed in a community which was approximately a thirty minute drive from their home community (which also had a special care home). This individual recognized there are competing needs. There is the need to efficiently place individuals in special care homes. There is the need to minimize those who are inappropriately kept in hospital waiting for a special care home bed. But there is also the need to include the individual and the family in the decision-making process. This family had no one in the community which was approximately a thirty minute drive from their home. The spouse who was staying at home would have no way to visit the spouse who was entering the special care home. The individual who related this story was a lawyer who has had involvement with special care homes in a professional capacity. The lawyer said, "I never dreamed that this existed (i.e. the 'first available bed policy' and its impact on families) until I experienced it firsthand."

"We don't recognize food choices."

— Interviewee quoting a staff member

Food was the most commonly mentioned topic throughout the interviews. The interviews suggest that meal times are times of stress, that staff make little effort to make meals pleasant. A

common complaint was that residents were not given adequate time or assistance to eat the meals provided for them. Specific issues included: Juice sealed in a container that could not be opened by the resident, and meals placed beside a resident who was unable to eat the meal without assistance. Many interviewees told me that they believed their loved one did not eat unless a family member, or someone they hired, was there to feed the resident. Three families believe their loved one died as a result of the lack of assistance available for residents to eat and drink.

Other food complaints related to the absence of or inappropriateness of food choice or of food preparation. Some residents require their food to be pureed in a blender. When this is done (in at least some facilities), the same food served to other residents is pureed. For example, in one case, a "blenderized" hot dog was served to a resident. A more acceptable choice, such as soup, was not offered.

It must be noted that these stories reflect interviewees' perceptions, not necessarily common practices in special care homes. Nevertheless, at worst, these perceptions indicate serious and unacceptable deficiencies of care. At best, they suggest a serious lack of communication and trust between special care homes and the families of residents.

Choice is the cornerstone of autonomy. While there must be some constraints on choice when one lives in a special care home, many interviewees felt more choice in the basic activities of the lives of residents could easily be attained. Many interviewees considered that residents' days were programmed largely for the administrative convenience of staff. The perception was that this, rather than respect for residents' need, controlled the time of waking, the time of dressing, bathing, eating, watching television, and virtually every other activity.

Other significant concerns were voiced concerning the personal care given in some special care homes. In some cases the perception held by family members was that personal care was neglectful or abusive.

Insufficient bathing (once per week for incontinent residents), inappropriate dressing and bathing (without respecting privacy) and inflexible personal care schedules were mentioned by some. Again, the perception of families and the perception of special care homes, as disclosed by the survey, seem to be different. Nowhere is this more evident than in regard to incontinence products. The survey clearly indicates that special care homes believe they do not limit the use of incontinent products. Although these products are paid for by residents, there is still an institutional cost to changing the product – it costs staff time and effort. Many family members' perception is that their loved one does not have their incontinence product changed sufficiently often, due to the unwillingness of staff members to change it more often. There was also a belief, although not voiced nearly so often, that with more staff and an appropriate bathrooming plan, fewer residents would require incontinence products.

Some family members expressed concern over bruises which appeared on their loved ones, coupled with what they saw as inadequate explanations for the bruising. Although abuse and neglect are beyond the scope of this project study, these stories raise matters directly on point. Whether these stories indicate uncorrected abuse or merely inadequate communication with families, an atmosphere of respect appears to be lacking in some cases.

There is some concern that some residents are being inappropriately medicated. In one case this meant that the resident was not getting required medicine on an appropriate schedule. In the rest of the examples, it meant that the interviewees perceived that residents were being medicated to make them more compliant or otherwise easier to deal with (chemical restraints). Interviewees expressed concern that if they complain, there may be retaliation against the resident. One interview indicated their family was told directly that if they insisted their loved one's medication be reduced, that the loved one would be moved to a different home. This would have serious implications on the ability of some family members to visit the resident.

One interviewee reported that a particular resident was always 'dopey' on Wednesdays. The family enquired about this, and was told that the resident, who was close to 100 years old, was agitated in the bath. Wednesday was 'bath day,' so the resident was sedated to lessen the agitation. The family asked the resident about this. The resident said "The water was always too hot, it burned my skin, and they wouldn't cool it off, so I'd protest."

While medications ought to be a medical matter between residents (or their representatives) and their doctors, this issue once again highlights concern over the lack of respect for the civil rights of residents as well as a lack of trust between family members and special care homes.

2.4.2 Staff/Bed Shortages

Staff and bed shortages can affect the perception that individuals have about the care their loved one receives. This theme obviously involves more than civil rights of residents, but civil rights are affected. Indirectly, an over worked and stressed staff is less able to find time to respect the individual needs of residents, and more directly, insufficient staffing and bed levels can destroy resident choice.

"Sometimes we spend so much time giving care that we forget how to care."

---- Staff member

Many families acknowledged the shortage of staff. Many in fact saw themselves as helping staff by taking on some tasks related to their loved one (such as feeding) which they viewed as staff's responsibility. Sometimes these shortages were cited as issues which led to not only poorer care, but more work for the staff. For example, one staff person indicated that when a resident buzzes for assistance many times, sometimes what they really need is someone to sit and

talk with them for a while. This investment of time may prevent many more buzzes.

Clearly staffing impacts on the personal care of residents, the choices offered to residents, the number of bathroom visits and incontinence changes a resident has, how often baths are taken and virtually all other areas of residents' lives. One family member suggested the development of a network of volunteers to feed residents as a partial solution. Two interviewees indicated that failure to replace absentee staff was commonplace (i.e. if a staff member was unable to come into work, they were not replaced so the shift would simply be shorthanded). Clearly, this would have a direct impact on the ability of staff to assist residents with the activities of daily living. One family member indicated that while at "full staff" one home begins putting residents into bed at 7:15 p.m.

2.4.3 Workplace-Home Conflict

This theme came up with many interviewees. The character of a special care home is that while it is a workplace for one group of people who belong there, it is the home of another group of people who belong there. Most of us have different expectations of how we will be treated in our own home than in the workplace. We expect greater privacy, more respect and greater choice in our homes. Workplace gossip about one's family for example, may be hurtful. More than one interviewee expressed the feeling that gossip by staff about a resident's family members can be deeply hurtful. This is amplified because it comes to the resident in their own home.

Smoking is an unpopular activity among many people. However, it remains a choice open for adults to make – and given the quantity of tobacco products sold in Canada, many adults choose to consume it. It can be argued that residents should have this choice in their own home. At the same time, most people who do not smoke would not tolerate smoking in their workplace. Staff at special care homes ought to be entitled to work in a smoke-free environment. These two

faces of a special care home must both be recognized, and some reasonable accommodation reached. Working in someone's home does not mean workers should lose all control over the workplace, but neither should having workers in their home mean that residents relinquish control of their home.

3. Protecting the rights of residents in long-term care

3.1 Need For Reform

Professor Surtees found that:

> The perception that residents and their families lack a voice came through loud and clear in interviews with family members. Families sometimes felt as if they had to learn how to maneuver through the health region structure in order to try to be heard. They felt as if they were at a disadvantage because this was the first time they had faced these issues, while staff faced them regularly. Many family members indicated they were concerned about retaliation against their loved one if they intervened too much. Residents were often seen as powerless, and residents without families as the ones in the worst situation.

Part of the perception that residents' rights are not respected may reflect poor communication, both between long-term care homes and residents, and between the homes and residents' families. But poor communication may itself evidence an atmosphere in which respect for rights is not given sufficient priority. Although long-term care operators are aware of issues of abuse, the impression left by the survey is that there is less institutional concern and less urgency to address the issues than residents and their families think is required.

There is wide agreement that improved education for staff and administrators about abuse is an indispensable step toward improving the living conditions of residents in long term care.[16]

[16]Saskatoon Council on Aging Older Adult Abuse Task Force presentation, *National Perspectives on Elder Abuse: Join the Conversation*, ONPEA Conference, November 3-4, 2009 Toronto, Ontario.

At present, the training in abuse awareness provided to staff of long-care home facilities is uneven. Programs referred to by respondents to the survey vary in focus, and there does not appear to be much emphasis in them on protection of civil rights or communication with residents and families. One way in which Saskatchewan Health and Regional Health Authorities could address the problems discussed in this paper would be development of workshops or presentations which could be used to educate staff of long-term care homes, residents and their families, and the public. Handbooks and training programs on abuse and protection of rights in long-term care are available.[17] Joanne Preston and Judith Wahl, *Abuse Education, Prevention and Response: A Community Training Manual for those who want to address the Issue of the Abuse of*

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[17] One of the major Canadian prevention initiatives is the "Abuse Prevention in Long Term Care" training program. It focuses on fostering a respectful environment for residents and staff:

Policy and Procedures Guidelines for Responding to and Preventing Abuse and Neglect; Abuse Prevention in Long-Term Care, Sisters of Charity of Ottawa Health Services Inc., Ottawa, Ontario, 1997.

The Ontario Nurses' Association has developed an extensive set of materials, including an abuse prevention guide, a workshop Facilitator's Guide, and a 27-minute video containing nurse-client scenarios and commentary:

One Too Many, College of Nurses of Ontario, 1999. (Video)
The Nurses' Workbook on Preventing Abuse, College of Nurses of Ontario,

Other resources include:

Policy and Procedures Guidelines for Responding to and Preventing Abuse and Neglect: Abuse Prevention in Long-Term Care, Sisters of Charity of Ottawa Health Services Inc., Ottawa, Ontario; 1997.

Long-Term Care Facilities in Ontario: The Advocate's Manual, 3rd edition, Advocacy Centre for the Elderly (ACE).

K. Pillemer, D. A, Menio, & B. Hudson Keller, *A Practical Guide for Prevention of Abuse in Long Term Care Facilities,* Frontline Publishing, 2001..

Connecting: A Curriculum Guide on the Abuse of Seniors, British Columbia Coalition to Eliminate the Abuse of Seniors, April, 1996.

Older Adults in their Community by, 3rd ed., Advocacy Centre for the Elderly (ACE), December 2002.

But as important as education is, it may not be enough in itself to effectively address abuse and rights issues. The law protecting the rights of residents in long-term care could be clarified and expanded to more directly address issues of abuse and civil rights.

The problem is not that there are no legal remedies for abuse and violations of rights. Civil rights are protected under Saskatchewan law. Abuse may give rise to criminal prosecution or a civil law suit. Saskatchewan legislation imposes certain specific duties on long-term care homes. A recent Saskatchewan Public Legal Education (PLEA) pamphlet, *Your Rights in a Special Care Home*, gathers and lists some of these legal protections in order to bring them to the addition of residents and care providers.[18] But the very fact that these protections are scattered in a variety of statutes, common law rules, and regulations make them inaccessible to those who need them most. The most effective legal mechanisms are those which bring rights and duties to the attention of staff, residents, and families, and which provide clear procedures for enforcing rights.

The Commission has reviewed recent initiatives in other jurisdictions and the recommendations of organizations and researchers involved with abuse and rights issues in institutions. It has identified several legal mechanisms that might be effective to enhance protection of the civil rights of residents in long-term care facilities. These are briefly presented here for discussion.

3.2 Residents' Bill of Rights

[18]See Appendix.

A "residents' bill of right" has been advocated as a vehicle for clarifying the rights of residents and informing residents, their families, and institutional staff about those rights. The Saskatchewan *Personal Care Home Regulations* contains a residents' bill of rights.[19] There is no legally-sanctioned bill of rights for residents in Saskatchewan special care homes, but the list of rights in PLEA's *Your Rights in a Special Care Home* amounts to a bill of rights, and could be adopted by special care homes. Several of the homes who responded to the Commission's survey indicated that they have adopted a bill of rights, and some others reported that they are in the process of doing so.

Manitoba requires that all long-term care homes adopt a residents' bill of rights.[20] Ontario has mandated a bill of rights for residents in government operated nursing homes since 1987, and for residents of municipal and private long-term care homes since 1997. It is contained, with some extensions, in new comprehensive legislation governing long-term care.[21] In the United States, the Federal Department of Health has encouraged the use of residents' bills of rights, and many states have adopted them in law.[22]

The residents' bills of rights examined by the Commission have much in common. All include general statements confirming the human rights and dignity of residents. The first enumerated right in the PLEA bill of rights is a good example of the language typical of these statements. It states that: "You have the right to be treated with dignity and respect and to be free from harassment, neglect, and physical, emotional or financial abuse." Some develop this theme in more detail than

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[19]The Personal care homes Regulation, , P-6.01 Reg (1996). See Appendix.

[20]*Personal Care Homes Standards Regulation*, Part 2, Man. Reg. 30/2005. Note that all Manitoba long-term care facilities are styled "personal care homes." See Appendix.

[21] *Long-Term Care Homes Act, 2007*, S.O. 2007 c. 8. See Appendix. The bill of rights is explained in a publication of the Advocacy Centre for the Elderly (ACE) and Ontario Community Legal Education (CLEO), *Every Resident: Bill of Rights for People Who Live in Ontario Long-term Care Homes,* September, 2008.

[22]Some representative examples: *Montana Long-Term Care Residents' Bill of Rights,* Mont. Stats. 50-5-1101; *Resident Bill of Rights (Nursing Homes),* Minn. stats.144A.44; *Managed Care Bill of Rights,* Article 44 of the New York State Public Health Law.

others. For example, some but not all, recognize a resident's right to practice their religion and attend religious services. The Saskatchewan personal care homes bill of rights differs from most of the bills of rights examined by the Commission by including some very specific rules. For example, it provides that residents have the right "to receive visitors privately at the home between the hours of 9 a.m. and 9 p.m. without giving prior notice to the licensee."

Even if a residents' bill of rights has no legal status, it can be a useful educational document for staff, residents, and their families. Legislating a bill of rights, adopting it by statute or regulation, may have some additional benefits:

1. A legislated bill of rights has "official status" that emphasizes the importance of the document and encourages compliance. Most of the bills of rights examined by the Commission seem to rely heavily on the assumption that an officially-sanctioned bill of rights will encourage staff to respect residents' rights, and encourage residents and their families to complain if they feel rights have been ignored.

2. A legislated bill of rights ensures that basic rights are enunciated for all long-term care residents. Some of the "unofficial" bills of rights examined by the Commission are likely too general and vague to be of much value. Manitoba offers a third alternative: It requires adoption of a bill of rights, and sets out some matters that must be included in it, but leaves each home to design its own document. One of the best examples of a bill of rights examined by the Commission was prepared by a Manitoba long-term care home which built upon the minimum content required by law.

3. Legislation can provide for enforcement. The new Ontario legislation provides that

> A resident may enforce the Residents' Bill of Rights against the licensee as though the resident and the licensee had entered into a contract under which

> the licensee had agreed to fully respect and promote all of the rights set out in the Residents' Bill of Rights.

Most older legislation mandating residents' bills of rights is silent on enforcement. The Saskatchewan personal care homes bill of rights provides that residents have the right "to register complaints to the licensee and, if desired, to the minister." Presumably, a violation of the bill of rights would be grounds for a complaint. Since operators of special care homes are licensed by the province, violations of the bill of rights might be grounds for reviewing a license or otherwise disciplining a licensee.

4. Legislation can make rules to ensure that the bill of rights is prominently displayed in homes and brought to the attention of residents and their families. *The Personal Care Homes Regulation* requires that the personal care homes bill of rights must be posted in a "prominent place in the home." Ontario and Manitoba make similar rules. Accessability and publicity are obviously necessary to ensure that residents' bills of rights are effective.

While residents' bills of rights almost certainly make a contribution to creation of an atmosphere in which the rights of residents in long-term care are respected, they should not be expected to solve problems by themselves. Ontario has had a bill of rights in at least some facilities since 1987, but the Advocacy Centre for the Elderly reports that violations civil rights remain all too common. Some other measures which might address the problem are discussed below.

3.3 Reporting abuse and the complaints process

As the Advocacy Centre for the Elderly observes,

> Even in the best homes, there are bound to be complaints. If residents or their loved ones know how to complain and have their issues resolved, they are

> more likely to be happy with the care at the home than if they have difficulties in resolving the problem . . . If one does not bring problems to the attention of the authorities, the problem may never be fixed. By being proactive, the homes can be improved for not only an individual resident but all of the residents living there.[23]

The Saskatchewan Health Quality Council encourages "patients (or their family members)" to resolve "questions relating to the health care services they receive" by following established complaints procedures.[24] There is no formal complaint procedure established by legislation or regulation for long-term care homes in Saskatchewan. However, complaints can be made to the home, health region or department of health. There are quality of care coordinators and client representatives in each health region. Saskatchewan Health states that

> If you have a question or a concern about your health care services, you may be able to resolve the issue by talking to the caregiver who provided the service, or to the appropriate supervisor. If this does not resolve your concerns, you may want to talk to the quality of care coordinator or client representative for your health region, or for the Saskatchewan Cancer Agency. There are also provincial quality of care coordinators at Saskatchewan Health. These representatives are available to help you by:
>
> * Answering questions or concerns about the health region's health services.
>
> * Ensuring you are aware of your rights and options.
>
> * Using your feedback to recommend changes and improvements to enhance the

[23]Jane E. Meadus, *Complaints about long-term care homes*, Advocacy Centre for the Elderly, January 2009.

[24]http://www.hqc.sk.ca/. The Health Quality Council is an independent agency established under *The Health Quality Council Act*, S.S. 2002, c. H-0.04.

quality of health services.[25]

However, the interviews conducted by Professor Surtees suggest that patients are not always aware of appropriate complaints procedure, and not always satisfied with the handling of complaints. There are some ways in which complaints procedure might be improved to better protect residents from abuse and give full respect to their rights.

1. Formal complaints procedure. Complaints procedures in Saskatchewan are not set out in detail in a readily accessible manner. Establishing a complaint procedure code would make the complaint process more transparent, certain, and publically accessible. Such a code could adopted by legislation or regulation.

Some other provinces have legislated complaints procedure, and given them wide public exposure. The Manitoba *Protection for Persons in Care Act*[26] is an example, though similar legislation has been adopted in Alberta, Nova Scotia, and Ontario.[27] The *Protection for Persons in Care Act* was enacted in 2001 as a result of public concern about abuse in health care facilities following the death of a resident in a care home.[28] The Protection for Persons in Care Office, which administers the Act, states that "the legislation created a formal process for reporting, investigating and resolving allegations of abuse in hospitals, personal care homes and Selkirk Mental Health Centre."[29]

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[25]http://www.health.gov.sk.ca/quality-of-care. The residents' bill of rights for personal care homes affirms the right of residents to make complaints, but sets out no procedure. Regulations applicable to special care homes do not deal directly with complaints.

[26]*Protection for Persons in Care Act,* C.C.S.M. c. P144

[27]See Appendix. For discussion complaints procedures in Ontario, see Jane E. Meadus, *Complaints about long-term care homes*, Advocacy Centre for the Elderly, January 2009.

[28]Darla Rettie, "Review: The Protection for Persons in Care Act," 28 *Man. L.J.* 245, 2001.

[29]The Protection for Persons in Care Office: Statistical Report 2008/09 (Manitoba).

2. Mandatory reporting of abuse. Several provinces, including Manitoba and Ontario, make reporting of incidents of abuse in long-term care home mandatory.[30] The Manitoba *Protection for Persons in Care Act* requires any person, including a caregiver, "who has a reasonable basis to believe that a patient in a health facility is, or is likely to be abused, to report the suspected abuse" to the Minister of Health or the Protection for Persons in Care Office. The act protects staff members and others from retribution for making an abuse report. An inquiry must be conducted by the Protection for Persons in Care Office when a report of abuse is received. 89% of complaints received by the Protection for Persons in Care Office have related to long-term care homes.

Mandatory reporting of abuse in long-term care, like similar requirements adopted to deal with child abuse, will likely focus attention on abuse, and increase the number of complaints. But experience with mandatory reporting suggests that it will improve out comes only if there are resources to handle the increased volume of complaints. Otherwise, reporting legislation may create a false sense that the problem of abuse is being addressed:

> Reporting legislation does not create solutions to abuse problems - it is only a means of people referring to a particular service to investigate. It appears attractive to other service providers who know that assisting a person who has been affected by abuse will take time and resources and/or who may feel that they lack the expertise to assist the older adult. Service providers may therefore prefer to pass on the matter to another person to deal with rather than help the older person themselves.[31]

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[30]See Appendix. A private member's bill to adopt a mandatory reporting and investigation system similar to Manitoba was introduced in Saskatchewan in 2002: *An Act respecting the Protection of Persons in Care*, Bill No. 205 of 2002.

[31]Joanne Preston and Judith Wahl, *Abuse Education, Prevention and Response: A Community Training Manual for those who want to address the Issue of the Abuse of Older Adults in their Community by*, 3rd ed., Advocacy Centre for the Elderly (ACE), December 2002.

In Manitoba, the number of complaints has risen in each year since the legislation was adopted, and stood at 1,375 in 2008/09. Full investigation has been deemed necessary in about 10% of cases, and of those, 79% were "founded." This is a substantial work load, but it appears to have been sustainable.

However, it has also been suggested that mandatory reporting legislation is itself an abuse of the rights of competent adults:

> Whether the reporting is voluntary or mandatory, this type of reporting legislation has been extensively criticized as an ageist and inappropriate response to a difficult and complex issue.
>
> It has been called ageist because it is based on childrens' legislation and does not reflect the rights of adults (such as the right to make informed choices) when made to apply to adult problems.
>
> Seniors are NOT children, they are adults. As adults, all older adults have the right to liberty and the right to choose how to live. It is unlikely that anyone wants to live in an abusive situation, however, some adults choose to live in abusive situations even after their options, in terms of leaving/getting out of this situation, have been explained. Adults also have the ability to make choices to remove themselves from difficult situations that are harmful and to take steps to seek help to address the abuse. Adults may choose the form of help, and the degree of help, that they want. [32]

The issue here may be whether an investigation will proceed against the wishes of the victim of abuse, not whether care givers and others should be required to report

[32]Joanne Preston and Judith Wahl, *Abuse Education, Prevention and Response: A Community Training Manual for those who want to address the Issue of the Abuse of Older Adults in their Community by,* 3rd ed., Advocacy Centre for the Elderly (ACE), December 2002. See also Coughlan, Stephen et al, *Mistreating Elderly People: Questioning the Legal Response to Elder Abuse and Neglect*, Halifax, 1995.

abuse. There is a public responsibility to deal with abuse in public institutions. Requiring the staff in long-term care homes to report observed incidents of abuse may be a significant way to recognize that responsibility.

3.4 Advocacy and Investigation

Good intentions can all too easily fail in practice. While a residents' bill of rights and mandatory reporting of complaints may make a contribution to the problem of abuse, a strong case can be made that neither will fully succeed unless residents and their families have access to knowledgeable, independent advocates and investigators committed to assisting residents to assert their rights. The experience of the Ontario Advocacy Centre for the Elderly shows that when an advocate is available to residents and their families, instances of abuse that otherwise go unnoticed are brought to light. In particular, instances of lack of respect for civil rights falling short of physical abuse seem more likely to be addressed when residents have an advocate. The Saskatoon Council on Aging has also argued that advocacy is essential to protect the rights of long-term care residents.[33]

A distinction should be made between investigation and advocacy. Investigation is an institutional response to complaints. The Manitoba Protection for Persons in Care Office is an example of an investigating agency as defined here. Under the *Protection for Persons in Care Act,* an inquiry must be conducted when a report of abuse is received. If there are "reasonable grounds to believe that a patient has been,

[33]Saskatoon Council on AgingOlder Adult Abuse Task Force presentation, *National Perspectives on Elder Abuse: Join the Conversation*, ONPEA Conference, November 3-4, 2009 Toronto, Ontario.

or is likely to be abused," the office then appoints an investigator. The PPCO defines its role thus:

* receiving reports of alleged abuse on a dedicated reporting line;

* conducting inquiries by reviewing and analyzing all alleged abuse reports for validity

and nature of complaint;

* conducting investigations on incidents of alleged abuse that appear to meet the

Threshold of abuse;

* making referrals of professionals to professional regulatory bodies for investigation;

* issuing directives to health facilities to improve policies and/or processes that

address the identification, reporting, prevention and management of patient abuse;

* conducting follow-up audits of selected facilities that have received directives.

Although the PPCO is a government agency, it is independent of direct control by the Department of Health. However, its role is circumscribed by its role as investigator of reported incidents of alleged abuse. An independent advocate, on the other hand, would have a broad mandate to represent residents and their interests. Violations of civil rights and low-level structural abuse are likely more apt to be caught by the activities of an advocate than an investigator. An advocate should be able to act on behalf of a client by lobbying for changes in care or house rules, negotiating, and even bringing appropriate legal action. In Ontario, the Advocacy Centre for the Elderly operates as a legal aide clinic funded by Ontario Legal Aide. This structure underlines the role of the advocate as residents' representative, but advocates could be employed by an independent agency similar to the Manitoba Protection for Persons in Care Office.

4. Conclusion and Questions for Consideration

The issues and question raised in this paper are difficult. They are also important enough to warrant our collective attention. We should, through the long-term care system we create, provide the highest quality of life that we can for residents. Compassionate and caring long-term care homes and their staff, as well as residents and their families, are well served when we provide appropriate structures for enunciating and safeguarding the civil rights of residents in long-term care.

This consultation paper is intended to provide background for a discussion about ways to protect the rights of residents in long-term care. The questions for consideration set out below are intended to help focus the discussion, but are hardly exhaustive of the issues raised here.

1. Are protections for the civil rights of residents in long-term care (special care and personal care homes) adequate at present?

2. Should a residents' bill of rights be required for all long-term care homes? If so, should it be legislated, or should each facility be required to adopt its own bill of rights?

3. Should investigation of complaints of abuse (including violations of civil rights) be mandatory? If so, should an independent investigative agency be designated to investigate, recommend, and direct remedies for abuse?

4. Should an independent advocate to represent residents and their interests be created?

Appendix 1

Special Care Home Questionnaire

Thank you for agreeing to complete this voluntary survey about the civil rights of residents of your facility. Please feel free to further explain any answers on the back of this questionnaire.

1. Are residents permitted to vote in: (please check all that apply)

? Federal elections ❑ Provincial elections ❑ Municipal elections

If so, do staff provide any assistance to residents to help them vote?

? Yes, we ask if they require assistance ❑ Yes, but only if residents ask for help ❑ No

2. Think of the staff seminars available to staff at your institution (either on-site or off-site, such as at a conference). Have any of these seminars been concerned with increasing the respect for civil rights of residents? ❑ Yes

❑ No

If "Yes", please list the topics and indicate approximately how many sessions were held:____

_____

_____

_____

_____

3. Are residents allowed to smoke?

? Yes ❑ Yes, provided they do not need assistance

❑ No

4. Are residents allowed to drink alcohol?

? Yes ❑ Yes, provided they do not need assistance

❑ No

5. Does your facility have a resident's council?

? Yes, and it is active ❑ Yes, but it is not active

❑ No

6. Does your facility have a document such as a 'Resident's Bill of Rights'?

? Yes, and we take steps to make residents and their families aware of it

? Yes, and we take steps to make residents aware of it

? Yes, but we do not take steps to make residents or their families aware of it ❑ No

7. Do you have a policy limiting either the number of incontinent products used by a resident, or the time a resident's incontinent product may be changed? ❑ Yes ❑ No

If "Yes", please describe the policy or attach it:

8. Do you have a policy regarding privacy for residents while they are being bathed or undressed? ❑ Yes

❑ No

If "Yes", please describe the policy or attach it:

_____

_____

_____

_____

Thank You

APPENDIX 2

YOUR RIGHTS IN A SPECIAL-CARE HOME (PLEA)

You have the right to decide how you want to live and to accept or refuse support, assistance or protection as long as you are not harming yourself or others and have the capacity to make these decisions.

You have the right to receive the most effective form of support, assistance or protection in the

least restrictive or intrusive manner when you are unable to care for yourself.

You have the right to be informed about decisions affecting you and, to the best of your ability, participate in making those decisions.

You have the right to be treated with dignity and respect and to be free from harassment, neglect, and physical, emotional or financial abuse.

You have the right to receive safe and adequate care. This means that you should receive considerate care in a pleasant environment and have your special needs looked after. Your care should include good personal hygiene and healthy nutritional practices.

You have the right to receive medical attention as required. A physician must be on call at all times. In the case of serious illness or accident, your family must be notified.

You have the right to have your personal health information treated in a private and confidential manner that is respectful of your best interests.

You have the right to privacy insofar as is possible. Part of being treated with respect includes respecting your privacy generally and particularly when receiving medical attention or personal care.

You have the right to participate, or not participate, in individual or group activities such as physical and recreational programs.

You have the right to attend, or not attend, religious or spiritual services inside or outside of the home.

You have the right to leave the home to visit, shop or take part in other social activities unless there is a good reason for refusing such permission.

APPENDIX 3

ONTARIO RESIDENTS' BILL OF RIGHTS

Long-Term Care Homes Act, 2007

S.O. 2007, CHAPTER 8

PART II
RESIDENTS: RIGHTS, CARE AND SERVICES

Residents' Bill of Rights

Residents' Bill of Rights

3. (1) Every licensee of a long-term care home shall ensure that the following rights of residents are fully respected and promoted:

1. Every resident has the right to be treated with courtesy and respect and in a way that fully recognizes the resident's individuality and respects the resident's dignity.

2. Every resident has the right to be protected from abuse.

3. Every resident has the right not to be neglected by the licensee or staff.

4. Every resident has the right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs.

5. Every resident has the right to live in a safe and clean environment.

6. Every resident has the right to exercise the rights of a citizen.

7. Every resident has the right to be told who is responsible for and who is providing the resident's direct care.

8. Every resident has the right to be afforded privacy in treatment and in caring for his or her personal needs.

9. Every resident has the right to have his or her participation in decision-making respected.

10. Every resident has the right to keep and display personal possessions, pictures and furnishings in his or her room subject to safety requirements and the rights of other residents.

11. Every resident has the right to,

i. participate fully in the development, implementation, review and revision of his or her plan of care,

ii. give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent,

iii. participate fully in making any decision concerning any aspect of his or her care, including any decision concerning his or her admission, discharge or transfer to or from a long-term care home or a secure unit and to obtain an independent opinion with regard to any of those matters, and

iv. have his or her personal health information within the meaning of the Personal Health Information Protection Act, 2004 kept confidential in accordance with that Act, and to have access to his or her records of personal health information, including his or her plan of care, in accordance with that Act.

12. Every resident has the right to receive care and assistance towards independence based on a restorative care philosophy to maximize independence to the greatest extent possible.

13. Every resident has the right not to be restrained, except in the limited circumstances provided for under this Act and subject to the requirements provided for under this Act.

14. Every resident has the right to communicate in confidence, receive visitors of his or her choice and consult in private with any person without interference.

15. Every resident who is dying or who is very ill has the right to have family and friends present 24 hours per day.

16. Every resident has the right to designate a person to receive information concerning any transfer or any hospitalization of the resident and to have that person receive that information immediately.

17. Every resident has the right to raise concerns or recommend changes in policies and services on behalf of himself or herself or others to the following persons and organizations without interference and without fear of coercion, discrimination or reprisal, whether directed at the resident or anyone else,

i. the Residents' Council,

ii. the Family Council,

iii. the licensee, and, if the licensee is a corporation, the directors and officers of the corporation, and, in the case of a home approved under Part VIII, a member of the committee of management for the home under section 132 or of the board of management for the home under section 125 or 129,

iv. staff members,

v. government officials,

vi. any other person inside or outside the long-term care home.

18. Every resident has the right to form friendships and relationships and to participate in the life of the long-term care home.

19. Every resident has the right to have his or her lifestyle and choices respected.

20. Every resident has the right to participate in the Residents' Council.

21. Every resident has the right to meet privately with his or her spouse or another person in a

room that assures privacy.

22. Every resident has the right to share a room with another resident according to their mutual wishes, if appropriate accommodation is available.

23. Every resident has the right to pursue social, cultural, religious, spiritual and other interests, to develop his or her potential and to be given reasonable assistance by the licensee to pursue these interests and to develop his or her potential.

24. Every resident has the right to be informed in writing of any law, rule or policy affecting services provided to the resident and of the procedures for initiating complaints.

25. Every resident has the right to manage his or her own financial affairs unless the resident lacks the legal capacity to do so.

26. Every resident has the right to be given access to protected outdoor areas in order to enjoy outdoor activity unless the physical setting makes this impossible.

27. Every resident has the right to have any friend, family member, or other person of importance to the resident attend any meeting with the licensee or the staff of the home. 2007, c. 8, s. 3 (1).

Further guide to interpretation

(2) Without restricting the generality of the fundamental principle, the following are to be interpreted so as to advance the objective that a resident's rights set out in subsection (1) are respected:

1. This Act and the regulations.

2. Any agreement entered into between a licensee and the Crown or an agent of the Crown.

3. Any agreement entered into between a licensee and a resident or the resident's substitute decision-maker. 2007, c. 8, s. 3 (2).

Enforcement by the resident

(3) A resident may enforce the Residents' Bill of Rights against the licensee as though the resident and the licensee had entered into a contract under which the licensee had agreed to fully respect and promote all of the rights set out in the Residents' Bill of Rights. 2007, c. 8, s. 3 (3).

Regulations

(4) The Lieutenant Governor in Council may make regulations governing how rights set out in the Residents' Bill of Rights shall be respected and promoted by the licensee. 2007, c. 8, s. 3 (4).

APPENDIX 4

SASKATCHEWAN PERSONAL CARE HOMES REGULATIONS

RIGHTS AND PRIVILEGES OF RESIDENTS

Rights and privileges of residents

34(1) In addition to any other rights and privileges that the residents may have at law, each resident has the following rights and privileges:

(a) to be treated with respect, dignity, kindness and consideration in all interactions with staff, residents and other persons who reside in the home;

(b) to voice concerns or recommend changes in the rules or services provided in the home;

(c) to register complaints to the licensee and, if desired, to the minister;

(d) to attend religious services or activities of the resident's choosing;

(e) to be provided with personal privacy;

(f) to have sole use of his or her own possessions unless the resident gives permission for others to use those possessions;

(g) to receive visitors privately at the home between the hours of 9 a.m. and 9 p.m. without giving prior notice to the licensee;

(h) to communicate within the home by telephone or mail in private;

(i) to leave and return to the home as desired at all reasonable hours on notifying the licensee or the licensee's designate;

(j) to be free from any actions from the licensee or staff of a punitive nature, including physical punishment, threats of any kind, intimidation, verbal, mental or emotional abuse or confinement;

(k) to choose his or her own medical, optometric, dental, nursing or other health care professional.

(2) A licensee shall ensure that the rights and privileges mentioned in subsection (1)

are respected.

17 May 96 cP-6.01 Reg 2 s34.

Resident and family meetings

34.1 A licensee must organize a meeting at least twice in each year for residents, the family members of residents and supporters for the purpose of promoting the interests of residents and their involvement in decisions that affect their day-to-day living.

23 Aug 2002 SR 69/2002 s24.

Posting

35 A licensee shall post a copy of the following in a prominent place in the home:

(a) the residents' rights and privileges mentioned in section 34;

(b) the rules of the home.

APPENDIX 5

MANDATORY REPORTING AND INVESTIGATION OF ABUSE

Province or Territory	**Mandatory reporting for abuse in institutions?**	**Types of harms covered by the law or regulations on institutions to be reported**	**Any protection for reporting**	**Any penalty for not reporting?**
Alberta	Yes. *Protections for Persons in Care Act* but only if it is a publicly funded facility	Intentional harms. (bodily harm, emotional harm, sexual abuse, inappropriately administering medications, financial abuse, neglect.	Yes. no action against reporter unless the report is made; no reprisal against person in care	Yes, under *PPCA*. Can be fined.

British Columbia	*In Part.* *Community Care and Assisted Living Act* : -Operator required to report "reportable incidents" in licensed community care facilities (complex care).] -No similar reporting requirement for abuse or neglect occurring assisted living facilities. - Part 3 of *Adult Guardianship Act*, covers community and institutions. -Has voluntary reporting in general, but duty on designated agencies to report crimes occurring in community or institution to the police.	*CCALA* covers neglect, emotional, physical, sexual and financial abuses in community care facilities only. *AGA* covers Emotional abuse, Financial abuse, Physical abuse, Sexual abuse, and Neglect	*Yes. CCALA* and *AGA* protection from lawsuits for reporting abuse or neglect in licensed long term care facility as long as made in good faith; protection for person in care- protection from reprisals	None.
Manitoba	Yes. (*Protections for Persons in Care Act*) Applies to hospitals, personal care homes and other health facilities as determined by regulation.	Physical , sexual, mental, emotional, and financial abuse.	Yes. Immunity from proceeding or other action, if reporting abuse of vulnerable person in good faith Protection of employment for reports made in good faith. No retaliation against resident or person making report	Yes, up to $2,000 fine for individual, $30,000 for corporation. $2,000 fine for false report.

New Brunswick	No specific reporting provision, but under *Nursing Home Act*, the operator has duty to report "major incident or accident affecting health or safety of residents or staff."			Operator may be fined $500 to $10,250 for failure to report major incident in nursing home; or imprisonment up to 180 days
Newfoundland	No.			
NWT	No.			
Nova Scotia	Limited. *Homes for Special Care Act* requires report of "unusual occurrences" in a form once every three months. Applies to nursing homes, homes for the aged, and residential care facilities. (*Protection of Persons in Care Act*, not yet in force, will extend mandatary reporting requitements).		No.	any contravention of the *Act* can carry fine of up to $100, or imprisonment up to 30 days.
Nunavut	No.			

Ontario	In part. By regulation under *Nursing Homes Act*, *Charitable Institutions Act, Homes for the Aged and Rest Homes Act*, facilities are required to report any assault or any injury where taken to hospital, or accidental/ unexplained death. These are consolidated in the *Long Term Care Homes Act*, 2007, not yet in force.	*Nursing Home Act* applies to : mental and physical abuse, violation of certain rights, improper use of restraints.	Yes. Protection from reprisals when making disclosure to inspector (under all three Acts), protection of job if reporting (under NHA), as long as made in good faith.	Contravention of almost any section of the NHA is an offense. On conviction, may carry fine up to $25,000 or jail up to one year for the 1st offense by an individual. Fine on first offense is up to $50,000 for a corporation.
PEI	Under *Community Care Facilities and Nursing Home Act* an "incident report" is required to record "injury, medication or treatment error,." But no report to outside authority is required.		Yes, *Adult Protection Act* offers protection from lawsuit as long as report not made maliciously or without reasonable and probable cause. [However, the does not specifically apply to institutions]	
Quebec	No.			

Saskatchewan	In part. Under regulations to the *Personal Care Home Act,* operator must report all "serious incidents" to resident's supporter and health authority. Abuse and neglect are defined as "serious incidents." No specific reporting requirement applies to special care homes. Under policy guidelines adopted in 2004, "critical incidents" in health care facilities must be reported to Saskatchewan Health.	Reportable incidents under *PCHA* include "Any harm or suspected harm suffered by a resident as a result of unlawful conduct, improper treatment or care, harassment or neglect on the part of any person, any occurrence, accident or injury that is potentially life threatening, and deaths reportable to Corner." A critical incidents is "a serious adverse health event including, but not limited to, the actual or potential loss of life, limb or function related to a health service provided by, or a program operated by, a regional health authority (RHA) or health care organization (HCO)."		Under PCHA, any violation carries a fine up to $1000 for an individual, and $5000 for a corporation, with additional $200 fine for the individual for each day the offence occurs, and $1000 a day in the case of a corporation.
Yukon	No.			

Adapted in part from Canadian Network for the Prevention of Elder Abuse, April 2009.