



# Psychiatric Patient Advocate Office

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## *PPAO Submission*

### *Future Directions for Legislation Governing Long-Term Care Homes*

December 15, 2004

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**PROMOTING PATIENTS' RIGHTS**



# Psychiatric Patient Advocate Office

Bureau de l'intervention en faveur des patients des établissements psychiatriques

December 15, 2004

Hon. George Smitherman M.P.P.  
Minister of Health and Long-Term Care  
10<sup>th</sup> Floor, Hepburn Block, 80 Grosvenor Street  
Toronto, Ontario, M7A 2C4

Dear Minister Smitherman:

Thank you for the opportunity to participate in the consultation process relating to the "Future Directions for Legislation Governing Long-Term Care Homes." We are pleased with the Ministry's efforts to strengthen and consolidate the legislation for Ontario's Long-term Care Homes and to make necessary reforms in the current service delivery system.

As a rights protection organization, we believe that many of the rights protections currently enjoyed by clients in the mental health sector should be extended to Ontario's long-term care sector. This would include the extension of formal rights advice to residents of long-term care facilities when found incapable of consenting to treatment, when made financially incapable or when found incapable of consenting to admission to a long-term care facility. In each of these situations, formal rights advice would ensure that the resident was advised of their rights and options and given assistance in exercising those rights, if they wished to do so.

We believe that residents in Ontario's long-term care homes should have access to an independent non-legal advocacy and rights protection program. An independent advocate could help residents navigate a complex health delivery system, support them in self-advocacy efforts, give a voice to the issue when unable to speak for themselves, assist with problem resolution and engage in systemic advocacy. This would reduce the vulnerability of the resident and provide a rights protection perspective not currently enshrined in long-term care. The work of the advocate would complement and supplement the work done by the Resident and Family Councils, and on some issues they would work collaboratively.

The PPAO model of social and non-legal advocacy and rights advice has proven to be an effective service delivery model over the last two decades and the work of the office has brought about significant improvements in the mental health sector. This model could easily be adapted to the long-term care sector. If we can be of any assistance in the design, implementation and evaluation of an advocacy model for Ontario's seniors we would be pleased to assist. Should you have any questions or wish to discuss our submission, please contact me at (416) 327-7007.

Sincerely,

Vahe Kehyayan  
Director

## Summary of Recommendations Psychiatric Patient Advocate Office

- The PPAO recommends that the government adopt a broad definition of quality of life and work with stakeholders to develop an inclusive and encompassing definition.
- The PPAO recommends that the government adopt a rights protection strategy comprised of both independent advocacy and rights advice services for residents of long-term care homes (LTC Homes).
- The PPAO recommends that residents' of LTC homes have access to a full range of specialized mental health supports and services within their long-term care home.
- The PPAO recommends that the Ministry of Health and Long-Term Care set provincial standards for access to and delivery of a full range of mental health care services and supports in LTC homes in Ontario.
- The PPAO recommends that the Ministry of Health and Long-Term Care require LTC Home staff receive training and education on mental health and mental illness to provide for early intervention, assessment and appropriate treatment.
- The PPAO recommends that a person's mental illness not become a barrier to placement in a LTC Home of choice.
- The PPAO recommends that appropriate resources be devoted to supporting individuals with mental illness in LTC Homes, including admission to their home of choice.
- The PPAO recommends Residents' Councils continue to be fully funded and fully autonomous.
- The PPAO recommends that the provincial umbrella organization continue to be funded and resourced appropriately to provide the necessary support, training and education to Residents' Councils.
- The PPAO recommends that residents and families be involved at all levels of the organization including: policy and procedure committees, hiring committees, program planning and evaluation committees, social and recreational committees, and best practice and standards committees.
- The PPAO recommends that Family Councils continue to be fully funded and autonomous.

- The PPAO recommends that all information about the LTC Home be available to residents and families so that they can make an informed decision about admission to the home or continuing their stay at that specific home.
- The PPAO recommends the extension of formal rights advice to the LTC sector when residents are found incapable of consenting to treatment, financially incapable or incapable of consenting to admission to a LTC Home.
- The PPAO recommends the establishment of an independent seniors' advocate to protect the legal and civil rights of seniors residing in LTC Homes in Ontario.
- The PPAO recommends that the government set standards and devote resources to assist LTC Homes in moving towards a "hands free" or restraint free environment.
- The PPAO recommends that the government require annual training for staff involved in the use of restraints.
- The PPAO recommends that the government codify in legislation documentation standards for when restraints have been used, including: the length of time in restraints, the reason, the behaviours exhibited, if a chemical restraint has been used, the least intrusive alternatives offered and require an assessment and doctor's order prior to the individual being placed in seclusion.
- The PPAO recommends that the Ministry require mandatory reporting of abuse and other unlawful acts in LTC Homes.
- The PPAO recommends that the Ministry ensure that there be significant sanctions for those who fail to report abuse and other unlawful acts.
- The PPAO recommends that LTC Homes be required by law to make a mandatory report to the College of the regulated health practitioner when abuse or unlawful acts in their Home are suspected.

## Residents' Quality of Life and Standards of Care

### Quality of Life:

Setting standards for the delivery of quality care for residents is an excellent first step to enhance their quality of life. However, we would encourage the government to define quality of life broadly and to involve stakeholders in defining the parameters of this definition. Quality of life may include, but not be limited to the following:

- having the right to choose where to live,
- daily access to fresh air out of doors,
- to live in an environment free of abuse,
- to have services provided in your first language,
- to have services provided in keeping with ethnicity, heritage and cultural background,
- access to French language services, as desired,
- having qualified health practitioners to deliver care, services and treatment,
- the right to live with your spouse,
- not to be overmedicated or have medications hidden in food or beverage,
- access to appropriate physical and mental health care,
- no treatment without consent,
- the ability to be a whistleblower without fear of being panelized or victimized,
- access to a variety of nutritional foods,
- opportunities to stay connected to the community,
- fostering diversity and inclusion,
- zero tolerance for discrimination based on ageism or other protected grounds in Ontario human rights legislation,
- having a comfortable home environment,
- having access to meaningful activities that enhance quality of life,
- strengthening relationships,
- be able to make an informed decision about smoking and have that decision respected,
- having a private space to call your own,
- being able to lock up personal belongings,
- having a decent, affordable and safe place to live without fear of not being able to afford it,
- having your rights protected and respected, including provision of formal rights advice by a qualified rights adviser,
- having your choices and decisions respected,
- being able to participate in activities of daily living at your own pace,
- ability to be an active participant in all decisions that affect your life, care and treatment,

- having access to individualized services and supports and being treated with dignity and respect.

Dignity, respect and autonomy of the person must be the cornerstones on which all other aspects of care are built. Without these, residents will not be able to live out their remaining years with dignity and comfort. Ontario's seniors must be able to live full and meaningful lives while making informed decisions about their care, life and treatment. All too often others make best interest decisions on their behalf and often there is no consultation with the resident about their wishes, needs, desires or decisions. This must change if the system is to become resident focused and accountable to the people that it serves. Stigma and discrimination impacts on residents in many ways due to beliefs and stereotypes that seniors, because of their age are not capable of making decisions, don't know what they want, or, because of diminished capacity or health concerns a best interest decision is made for them. This cannot continue to happen in a resident-centered LTC sector focused on rights and entitlements.

The PPAO recommends that the long-term care sector develop a resident-first and resident-centered system where the individual would be the centre of the system. This would enable residents to have a greater and equal voice. The reformed system would have a renewed interest in individual rights and where more complex care needs are matched with increased accountability and strengthened quality assurance mechanisms based on best practices. Empowerment, self-determination, and self-advocacy supported by a wellness and recovery focus would strengthen these reforms.

### **Recommendations:**

- The PPAO recommends that the government adopt a broad definition of quality of life and work with stakeholders to develop an inclusive and encompassing definition.
- The PPAO recommends that the government adopt a rights protection strategy comprised of both independent advocacy and rights advice services for residents of Long-Term Care Homes (LTC Homes).

### Access to a Full Range of Mental Health Services:

Residents may require access to a full range of mental health services during their stay in a LTC Home. Need or “acuity” has been increasing steadily over the past 10 years. The Ministry of Health and Long-Term Care estimates that the sector’s 67,000+ residents have increasing care requirements and medically complex needs including: 70% are 80 years or over, average age at admission is 82, and 65% have Alzheimer’s, dementia, or some other form of mental disorder.

However, a full range of specialized mental health services and supports are not readily available nor are they easily accessible at this point in time. This must change if residents are to receive appropriate mental health care that adequately addresses their needs and enhances quality of care and life. Any treatment provided must also be in keeping with the Health Care Consent Act and consent must be obtained before treatment is provided.

Residents may require access to crisis intervention services, independent counseling and support services, mental health assessment and treatment and specialized care when acutely ill. These services must be available within the LTC Home as residents should not be removed from their home just so they can access appropriate mental health care and treatment. If this were the case, many residents would be afraid to disclose that they need help for fear of losing their home and all that is familiar to them. Services, supports and treatment must be available and accessible in a timely manner and delivered in keeping with provincial legislation. These services may be important following the death of a spouse or roommate, for treatment of depression or dementia or other mental health issues related to feeling isolated, alone or facing end of life decisions. Access to a full range of specialized mental health services and supports must be seen as an essential component of quality care delivery to Ontario's seniors.

#### **Recommendations:**

- The PPAO recommends that residents' of LTC Homes have access to a full range of specialized mental health supports and services within their LTC Home.
- The PPAO recommends that the Ministry of Health and Long-Term Care set provincial standards for access to and delivery of a full range of mental health care services and supports in LTC Homes in Ontario.
- The PPAO recommends that the Ministry of Health and Long-Term Care require LTC Home staff receive training and education on mental health and mental illness to provide for early intervention, assessment and appropriate treatment.

#### Admission and Eligibility:

The current provincial placement co-ordination system appears to be meeting the objectives set out by the government. However, some residents who have a "mental health history" have reported to advocates that the placement assessments all too often focus negatively on their mental health needs, use inflammatory language to describe their needs or focus on a specific incident that is then used to illustrate risk, liability or dangerousness. This tends to diminish their chances for a placement of their choice in an "A" class facility.

If there has been any acting out or aggressive behaviour when they were ill this often becomes the focus of any placement discussion. This can be stigmatizing and may result in them being viewed "differently" by the service and care provider and may lead to an intolerance for behaviours that may be part of their illness.

Mental health needs must be considered like any other medical needs and the required treatments and support services must be accessible within the home.

**Recommendations:**

- The PPAO recommends that a person's mental illness not become a barrier to placement in a care home of choice.
- The PPAO recommends that appropriate resources be devoted to supporting individuals with mental illness in long-term care homes, including admission to their facility of choice.

Residents' Councils:

The PPAO is supportive of the inclusion of Residents' Councils in every LTC Home in the province, provided that they are fully funded and fully autonomous. This will increase their effectiveness and heighten accountability while ensuring that the delivery of services is resident-centered and resident focused. Inclusion of Residents' Councils will provide the resident perspective at all levels of the organization and allow for residents to have a "voice" in the decision making process. Homes should seek out ways to maximize resident input and avoid "tokenism" or limiting the way in which residents are involved or provide their input.

Councils will require various levels of support and assistance if they are to be effective. Such support and assistance could continue to be provided by a provincial umbrella organization, if properly resourced, that would provide advice, consultation services, support, training and education and assist with the development of resident-centered best practices. Councils may also require support with administrative duties and other tasks where there is a reporting relationship.

The inclusion of Residents' Councils is a positive enhancement that will strengthen the long-term care sector in Ontario.

**Recommendations:**

- The PPAO recommends Residents' Councils be fully funded and fully autonomous.
- The PPAO recommends that residents be involved at all levels of the organization including on policy and procedure committees, hiring

committees, program planning and evaluation committees, social and recreational committees, and best practice and standards committees.

- The PPAO recommends that a provincial umbrella organization continue to be funded and resourced appropriately to provide the necessary support, training and education to individual Residents' Councils.

### Family Councils:

Family Councils provide an excellent mechanism for family involvement in the delivery of services in long-term care homes. Family Councils however, should continue to be a separate entity from Residents' Councils as their work and interests may vary or be very different. Again, these councils should be fully funded and autonomous and have a significant role in the functioning of the facility and the services provided to their loved ones. Involvement must be encouraged, Council membership should reflect the diversity of the residents and their input should be reflected in the operations and decisions taken by the facility.

### **Recommendations:**

- The PPAO recommends that Family Councils be fully funded and autonomous.
- The PPAO recommends that families be involved at all levels of the organization including on policy and procedure committees, hiring committees, program planning and evaluation committees, social and recreational committees, and best practice and standards committees.

### Posting Information for Residents, Families and the Public:

Posting information for residents, families and the public is a necessary first step. However, education of stakeholders is essential if the posting of information is to achieve its desired objectives. For instance, individuals may not be aware of what the information means, or, how to file a complaint when there is an infraction.

In addition to posting the service agreement, the most recent inspection report and procedure for making a complaint there must also be a requirement that provincial legislation be available. Other information that must be posted or made available, should include the Resident Bill of Rights, policies regarding restraint, abuse and discrimination and other supporting information so that residents and their families can make an informed decision. Information must also be made available to residents and families regarding the homes history of infractions and provision of care.

**Recommendation:**

- The PPAO recommends that all information about the long-term care home be available to residents and families so that they can make an informed decision about admission to the facility or continuing their stay at that specific home.

## Residents' Rights and Safeguards

### Extension of Formal Rights Advice to the Long-Term Care Sector:

Currently, residents in Ontario's LTC sector do not receive formal rights advice where significant legal decisions are made that impact on their individual rights and freedoms. For example, if the person is found incapable of consenting to placement in a long-term care facility, found treatment or financially incapable, the health practitioner making the finding must provide rights "information" to both the incapable person and their substitute decision-maker. This potentially raises the issue of a real or perceived conflict of interest on the part of the health care practitioner making the finding. This is a lower standard of protection that those in the mental health system receive as clients in that sector receive formal rights advice when their legal status is changed or a significant decision made that directly impacts on their rights. In the mental health system an independent and certified Rights Adviser would meet with the client to provide them with information about their legal rights and options and then assist them in exercising those rights should the client wish to do so. The Psychiatric Patient Advocate Office provides rights advice in the 10 current and divested provincial psychiatric hospitals and in 54 of the 59 Schedule 1 facilities in Ontario. This results in almost 20,000 rights advice visits per year.

If the government is committed to maximizing rights protections for residents of Ontario's LTC sector, they would extend the provision of formal rights advice to every LTC Home in the province to ensure that residents are aware of both their legal rights and options. Rights advice would reduce the vulnerability of this population and ensure that they were aware of their rights and have assistance in exercising those rights.

**Recommendation:**

- The PPAO recommends the extension of formal rights advice to the LTC sector when residents are found incapable of consenting to treatment, financially incapable or incapable of consenting to admission to a LTC Home.

### Access to an Independent Advocate:

Many residents are vulnerable because of their life circumstances, their illness, frailty, not knowing how to navigate a complex system or where to turn for help or information and many may be isolated without family or significant others to advocate on their behalf.

As a rights protection organization, the PPAO believes that the LTC sector would be strengthened by the inclusion of an independent advocate who is empowered to advocate on behalf of residents who could not or need assistance to speak for themselves. The Seniors' Advocate could report annually on the sector, make recommendations to government for systems improvements and ensure that the voice of residents and families were heard by the decision makers. Where residents and families were able to advocate on their own behalf, the Seniors' Advocate would support their work and provide advice and consultation. It would be essential for the Seniors' Advocate to complement and supplement the work of the Resident and Family Councils and to work with stakeholders to identify system improvements and best practices for the long-term care sector.

### **Recommendation:**

- The PPAO recommends the establishment of an independent seniors' advocate to protect the legal and civil rights of seniors residing in LTC Homes in Ontario.

### Restraints:

Seclusion and restraint procedures not only represent a significant infringement of an individual's right to autonomy and self-determination but also are associated with significant morbidity and mortality. Whereas the risks of seclusion and restraint have been well established, the benefits remain uncertain. In some homes restraints are disguised as a safety and protective device when that truly is not the intended purpose for the restraint.

Restraints are often used inappropriately to control annoying behaviour, stop a resident from wandering or to make it easier to supervise the resident they are placed in a tray chair to restrict mobility. In some circumstances such restraint use is not in keeping with the spirit or intent of the legislation and may violate a person's rights. Ontario should set stringent standards for restraint use, require that all restraint use be reviewed by an internal committee and reported to the Ministry and to ensure that legislation is not "permissive" of restraint use. Restraint use must become the exception.

The Ministry should provide both resources and expertise in assisting facilities to move away from restraint use to provision of care in a "hands free" and restraint free environment. The PPAO's report "Review of Seclusion and Restraint

Practices in Ontario Provincial Psychiatric Hospitals: Perspectives of Patients, Clinicians and Advocates" is available at [www.ppaio.gov.on.ca](http://www.ppaio.gov.on.ca).

### **Recommendations:**

- The PPAO recommends that the government set standards and devote resources to assist facilities in moving towards a "hands free" or restraint free environment in LTC homes.
- The PPAO recommends that the government require annual training for staff involved in the use of restraints.
- The PPAO recommends that the government codify in legislation documentation standards for when restraints have been used, including: the length of time in restraints, the reason, the behaviours exhibited, if a chemical restraint has been used, the least intrusive alternatives offered and require an assessment and doctor's order prior to the individual being placed in seclusion.

### Duty to Report:

Some residents may be afraid to make a complaint about staff conduct, abuse or other unlawful acts out of fear that there will be some sort of retaliation or that they might be asked to leave the home. These fears could silence those who have legitimate concerns or be subject to abuse. Any duty to report must have enshrined in it an obligation on the home to protect the resident from reprisal or other negative consequences. Education for residents and their families would be required so that they are aware of the process, the protection for them enshrined in the law and to reassure them that the resident would not lose their home for making a complaint. If a home operator retaliated then there should be sanctions imposed as penalty.

If a senior's advocate were to be appointed, they could play a significant role in this process by advising the resident of their rights, providing information and support and if necessary, connecting them to services and supports. Having an advocate available to the resident would address any power imbalances or inequities and address access to resources issues.

If the government wishes to protect residents of LTC Homes then a mandatory duty to report both abuse and other unlawful acts must become a cornerstone of the proposed reforms. However, the government then must devote corresponding resources to ensuring that complaints are investigated, that complaints processes be timely and responsive, that there be authority to enforce required corrective action and where the law has been abridged to have legal sanctions available to the Court.

For those who fail to report, there should be significant penalties that reinforce the government's commitment to eliminating abuse and unlawful acts in LTC Homes. Standards for health practitioners must be even higher, requiring mandatory reporting by the home to the health practitioners regulating College. Such a requirement will heighten accountability of all parties and protect residents.

**Recommendations:**

- The PPAO recommends that the Ministry require mandatory reporting of abuse and other unlawful acts in LTC Homes.
- The PPAO recommends that the Ministry ensure that there be significant sanctions for those who fail to report abuse and other unlawful acts.
- The PPAO recommends that LTC Homes be required by law to make a mandatory report to the College of the regulated health practitioner when abuse or unlawful acts in their facility are suspected.

Conclusion

In conclusion, the Psychiatric Patient Advocate Office is pleased with the reforms envisioned by the Ministry of Health and Long-Term Care. The current willingness to improve the Long-Term Care system is encouraging and provides an excellent opportunity to reform the system to ensure that it is resident-centered, resident-focused and embodies best practices. The extension of formal rights advice to the LTC sector and the inclusion of an independent Seniors' Advocate would further strengthen the reforms envisioned by the Ministry while maximizing the rights of residents in Ontario's LTC Homes. The PPAO would be pleased to work with the Ministry to address rights protection issues.