



# Psychiatric Patient Advocate Office

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

September 13, 2005

Benedetto Saraceno  
Director  
Department of Mental Health and Substance Abuse  
World Health Organization  
20, Avenue Appia, CH-1211  
Geneva, Switzerland

Dear Benedetto:

## **International Forum on Community Mental Health Services**

The Psychiatric Patient Advocate Office (PPAO) is pleased to participate in the first-ever international forum on community mental health services and we would like to thank you for the opportunity to do so. Our submission will examine three key elements which should be considered by the World Health Organization as it embarks on its discussion of community mental health services. Our submission will address: 1) the need for independent advocacy, 2) development of a rights advice process to protect vulnerable individuals and 3) a public education campaign to combat the stigma and discrimination associated with mental illness. To learn more about our office please visit [www.ppao.gov.on.ca](http://www.ppao.gov.on.ca).

Although not addressed in our submission, we would also encourage WHO to consult on several other issues including: 1) the "definition of treatment" as it must include more than just medication, 2) timely access to mental health services and supports - both hospital and community-based, 3) greater involvement by consumer-survivors in the mental health system, 4) development of a global action plan to address issues related to mental health and addictions 5) access to medical services for individuals with mental illness and 6) adoption of a recovery orientation and focus for the mental health system, including forensic mental health.

Thank you again for the opportunity to participate in this forum and to address the issue of patients' rights and other rights protection mechanisms. If our office can provide any additional information or if you have any questions please do not hesitate to contact me at (416) 327-7004.

Sincerely,

David Simpson  
Director (Acting)

c.c. George Zegarac, Assistant Deputy Minister  
Ministry of Health and Long-Term Care



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*Submission to the World Health Organization  
International Forum on Community Mental Health  
Services*

*Independent Advocacy and Rights Advice:  
Supporting Recovery, Empowerment and Individual  
Rights*

September 2005

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**PROMOTING PATIENTS' RIGHTS**

## **About the PPAO**

The Psychiatric Patient Advocate Office (PPAO) was established in 1983 to protect the civil and legal rights of inpatients in the current and former provincial psychiatric hospitals in Ontario, Canada. As a rights protection agency with a "client first" philosophy, the PPAO promotes patients' rights by providing individual and systemic advocacy, rights advice and education. The PPAO undertakes these initiatives to improve the quality of care and life of all individuals with a mental illness and to protect and promote their civil and legal rights.

## **Independent Advocacy Services**

The PPAO provides independent advocacy services to individual patients (instructed and non-instructed), addresses facility-based or provincial systemic issues impacting on patients' rights, and facilitates consumer involvement and self-determination by providing support to patients with concerns about care, treatment or rights by way of facilitating their self-advocacy efforts. Advocacy is very different from "psychosocial rehabilitation" and both must be viewed as separate and distinct services.

The PPAO addresses approximately 3,500 individual advocacy cases annually in the ten current and former provincial psychiatric hospitals. Individual advocacy is advocacy that is undertaken directly by an advocate based on a client instruction. The process is guided by the principles of self-determination, client empowerment and self-advocacy. The advocate outlines options and the client determines the path to issue resolution. It is policy that the advocate assumes that the client is capable to instruct unless the contrary is indicated. Self-advocacy refers to advocacy that is undertaken directly by the individual to achieve a specific goal. This form of advocacy may be enhanced through contact with an advocate who can provide information, resources, and an outline of options and expected outcomes of an individual's actions.

The PPAO believes that advocacy, if done well, will improve outcomes, enhance the quality of care and life of individuals, protect human rights and heighten accountability by service providers to the client. Advocacy empowers clients and assists them in their recovery by supporting them to be involved in all decisions that affect their care, life and treatment. It ensures that individuals are aware of their rights, that they have choices and options and the support necessary to both make informed decisions and to act on them. Advocacy supports people in retaining responsibility for their own wellness and recovery and safeguards their human rights, in an environment of respect and inclusion.

Independent advocacy must be seen as a unique and discrete position within the mental health service delivery system, the same as the position of case manager, nurse or physician are considered to be distinct positions. To address inequities and injustices, all individuals with mental illness should be guaranteed access to such services, whether

they receive their care and treatment in the hospital or the community. Independent advocacy addresses power imbalances, inequities and discrimination, assists clients to resolve issues, allows the advocate to give a voice to an issue if the client is unable to do so and supports the client as a partisan and independent advocate who is there "for the patient." Advocates also work to connect clients to services, supports and programs that address specific issues related to income, housing, employment, social and recreational opportunities, other social determinants of health and a range of activities that support their wellness and recovery.

Independent advocacy must be seen as a partisan service for clients that supplements, complements and supports any rehabilitation model, as a unique service. It must not be viewed as a threat to the service provider community but instead as a partner in providing a full range of mental health services to clients.

The PPAO addresses approximately 75 systemic issues annually impacting on the quality of care, life and rights of a large number of patients. Systemic advocacy efforts are largely aimed at promoting change in the way the mental health system delivers services to the people it is intended to benefit.

These initiatives may, for example, include strategic efforts to change administrative structures and service delivery within the context of psychiatric institutions. This may include law and policy reforms that provide the basis for services provided in the mental health care system. The goal of systemic advocacy is to promote changes that support the legal rights, social and therapeutic entitlements of clients; and to address power inequities inherent in traditional institutional settings. Examples of PPAO systemic advocacy efforts include: advocating for changes to the Social Housing Reform Act, mandatory inquests when a patient dies in a mental health facility, increasing the Personal Needs Allowance for psychiatric patients, the Discharge Planning Report and advocating for inclusion of independent advocacy and rights advice services in the long-term care sector.

## **Rights Advice**

There is no more significant infringement of an individual's rights, freedoms and liberties than when they are involuntarily detained by the authority of the state. This is especially true if the individual is held in a mental health facility. The PPAO believes that the principles of natural justice, administrative fairness and consideration for human rights require that an independent Rights Adviser meet with the individual and inform them of the reason for the detention, their rights regarding the detention, and how to exercise those rights, if they so choose. The Rights Adviser will follow the individual's instructions and assist them in completing the necessary forms to activate the review process by an independent board, the Consent and Capacity Board.

In many countries, human rights are not respected and mental health clients receive even less protection under the law. Many people believe that mental health clients are not able to make decisions due to their illness and, as such, should not have rights protections in

place because they "don't know what they need." However, the Ontario experience, over the last two decades, has proven that clients can make informed decisions about their rights, if provided with the necessary information to do so and with the assistance of an independent Rights Adviser in exercising those rights. Thankfully, Ontario has aggressively protected the rights and entitlements of mental health clients and has developed a number of safeguards to protect those rights. Some of the safeguards are: provision of formal rights advice under mental health legislation, notification to the individual of the right to retain and instruct a lawyer, the right to apply for Legal Aid if you require a lawyer and cannot afford one; and the right to challenge the physician's finding before an independent board. Each of these safeguards plays a significant role in protecting the rights of individuals with mental illness and in creating a system of oversight and accountability.

Rights advice is a process by which patients in psychiatric facilities and persons being considered for Community Treatment Orders (CTOs) and their Substitute Decision-Maker (SDM), if any, are informed of their rights when their legal status has changed. Rights advice is an important component in the system of checks and balances established under the *Mental Health Act* (the *Act*) and its regulations (See Appendix 3) for the protection of the rights of the individual. Prior to the amendments to the *Act*, effective December 1, 2000 (Bill 68), rights advice was only provided to inpatients of psychiatric facilities. The amendments extended the provision of rights advice to persons living in the community and being considered for a CTO and their SDM, if any.

The eight situations in which the provision of Rights Advice is mandatory are:

- a physician's decision that the patient's status must change to involuntary;
- a physician's decision that the patient's involuntary status must continue;
- a physician's decision that the patient is incapable to manage his/her property, including finances;
- a physician's decision that the patient's incapacity to manage his/her property must continue;
- a physician's decision that the patient is incapable to consent to treatment for a mental disorder in circumstances set out in the Regulations under the Act;
- a determination that the patient is incapable of consenting to the collection, use or disclosure of personal health information in the circumstances set out in the Regulations under the Act;
- when a twelve to fifteen year old is admitted to a psychiatric facility as an informal patient, and every three months thereafter;
- before issuing or renewing a CTO, a physician must be satisfied that the person who will be subject to the CTO (and his/her SDM, if any) have consulted with a Rights Adviser and have been advised of their legal rights.

The World Health Organization should as part of its forum on community mental health services consider and support the inclusion of formal rights advice as a best practice in the development of any rights protection model for individuals with mental illness. The past two decades in Ontario have illustrated that it is effective in safeguarding patients'

rights, in bringing about systemic change and ensuring that the state is not heavy-handed in their approach to the delivery of mental health services. Ontario would be pleased to consult with the WHO on the development of a rights advice and rights protection model.

## **Public Education: Combating Stigma and Discrimination**

While the PPAO is most recognized for its advocacy and rights advice programs, it also maintains a long-standing commitment to public education surrounding mental health, and patients' rights. As with other highly stigmatized conditions, much progress is yet to be made in countering the widespread misconceptions surrounding people living with mental illness in Ontario. With rates of chronic mental illness expected to rise alongside an aging population, a broad-based public awareness campaign is necessary to reduce the barriers faced by this vulnerable population and to facilitate successful re-integration and repatriation of patients returning to their communities from mental health facilities. As more and more mental health care and treatment is delivered in community versus hospital, we need to begin thinking about the impact on the person, the health care system and the community at large. Investment in community-based mental health services and supports must include investment in independent advocacy and rights advice services.

The PPAO addresses the issue of stigma and discrimination, as a rights protection organization, through regular public speaking events, media publications, policy submissions, its website ([www.ppa.gov.on.ca](http://www.ppa.gov.on.ca)) and calls on all levels of government for clear legislation specific to mental health concerns.

In our view, an effective anti-stigma and discrimination program would require multi-level interventions that would address:

1. Systemic factors - policies, legislation, funding
2. Community factors - negative responses from media, police, general public
3. Health professional factors - their attitudes and responses to persons with mental illness and addiction
4. Individual factors - how stigma and discrimination affect an individual's self-identity, behaviour in seeking professional help, and successful recovery and re-integration into the community

The Ontario Government has recently taken the bold step of creating a public ministry devoted entirely to Health Promotion. It is hoped that the workings of this new office will effectively advocate for and raise the bar for public health knowledge of issues concerning mental health consumers and other vulnerable populations.

The PPAO would like to encourage WHO to review the development of any rehabilitation model to ensure that the language of the model is not discriminatory or stigmatizing for clients but instead based on the principles of recovery. For example, to have the word "psycho" included in the description of the model (psychosocial

rehabilitation) appears to be stigmatizing to some given what this term has come to represent in our popular culture. Language is powerful and must be used with discretion to ensure that it doesn't hurt the very people that it is intended to help.

## **Conclusion**

The PPAO is hopeful that the World Health Organization, Department of Mental Health and Substance Abuse will consider the recommendations in our submission and clearly articulate the need for inclusion of independent advocacy and rights advice as part of any community-based psychosocial rehabilitation service. Advocacy and rights advice protect the rights and entitlements of individuals with mental illness and must be considered as core services in any model put forth for consideration. In Ontario the PPAO has had a positive impact on the mental health system, respect for patients' rights and awareness of mental health legislation over the past two decades. It is from this vantage point that we would encourage the implementation of such rights protection services, as one way to protect individuals with mental illness, some of the most vulnerable members of our community.

## Appendix 1

### Glossary of Advocacy Terms

#### **Advocacy**

Advocacy is a process that ensures that the rights of vulnerable people are protected, that their self-defined needs are met, and that they are supported to make decisions that affect their lives. It is also a vital component of patient protection, assuring that the vulnerable person's legal and human rights are respected, and that their self-determination, independence and autonomy are maintained. The PPAO differentiates between the concepts of "protection" and "advocacy". "Protection" refers to interventions offered to people with disabilities on the assumption that they are unable to understand their options, express their views or make and take responsibility for choices about their lives, care and treatment. "Advocacy", on the other hand, emphasizes a person's capacity for autonomy and ability to make such choices, particularly if offered assistance in understanding the options available, and in communicating personal preferences to others. In the case where a vulnerable person cannot instruct an advocate and is at risk of abuse or neglect, an advocate's intervention may be seen as "protection." Hence, this dimension of "protection" is included within the concept of "advocacy."

#### **Self-Advocacy**

Advocacy that is undertaken directly by the individual to achieve a specific goal. This form of advocacy may be enhanced through contact with an advocate who can provide information; resources, and an outline of options and expected outcomes of an individual's actions.

#### **Instructed Advocacy**

Advocacy that is undertaken directly by an advocate based on a client instruction. The process is guided by the principles of self-determination, client empowerment and self-advocacy. The advocate outlines options and the client determines the path to issue resolution. The advocate assumes that the client is capable to instruct unless there is an indication to the contrary.

#### **Non-Instructed Advocacy**

In keeping with the principles of self-determination, client empowerment and self-advocacy, non-instructed advocacy is conducted on behalf of an individual who for some reason is unable to instruct an advocate at the given time. Issues may concern the quality of life of an institutionalized person or those where a failure to take action will compromise the health, estate, personal security or dignity of the client.

#### **Systemic Advocacy**

Systemic advocacy focuses on issues that affect a broad segment of a particular population. These initiatives may, for example, comprise strategic efforts to change administrative structures and service delivery within the context of psychiatric institutions. This can include law and policy reforms that provide the basis for services provided in the mental health care system. The goal of systemic advocacy is to promote changes that support the legal rights social and therapeutic entitlements of clients; and to address power inequities inherent in institutional settings.

## Appendix 2

### Guiding Principles of Advocacy

**Advocacy is Client Directed:** Unless the client is incapable of instructing an advocate, advocacy is client directed. That is, the actions of the advocate are guided by the instructions of the client. The advocate serves the client on a voluntary and consensual basis. The advocate does not substitute for the client's instructions his or her own personal or professional view of what course of action is in the "best interests" of the client. Central to advocacy is the determination of the client's wishes and the servicing of those wishes, unless the client's instructions are illegal or impossible to carry out.

**Advocacy is Independent:** Advocacy should be, and be seen to be, independent. In order to avoid any potential or perceived problems with conflict of interest, advocates should be independent both from the psychiatric facilities where and service providers from whom their clients receive care and treatment.

**Advocacy is Accessible:** For advocates to be able to assist vulnerable clients, they must be readily accessible to them. They must also be assured of the opportunity to communicate with their clients without interference from others.

**Advocacy Uses Avenues of Least Contest:** Advocates seek to resolve issues at the level of least contest by beginning with the decision-maker closest to the client's problem before escalation to higher authorities. They seek all avenues to promote patients' rights and freedoms including conciliation, mediation and reasoned discussion.

## Appendix 3 Role of the Rights Adviser

The role of the Rights Adviser is established under the Mental Health Act and its Regulations. Section 1(1) of the Mental Health Act defines Rights Adviser as

" a person, or a member of a category of persons, qualified to perform the functions of a rights adviser under this Act and designated by a psychiatric facility, the Minister or by the regulations to perform those functions, but does not include, (a) a person involved in the direct clinical care of the person to whom rights advice is to be given, or (b) a person providing treatment or care and supervision under a community treatment plan."

Rights advice is a process by which patients in psychiatric facilities and persons being considered for Community Treatment Orders (CTOs) and their substitute decision-maker, if any, are informed of their rights when physicians change their legal status. Rights advice is mandatory in eight situations:

- a physician's decision that the patient's status must change to involuntary;
- a physician's decision that the patient's involuntary status must continue;
- a physician's decision that the patient is incapable to manage his/her property, including finances;
- a physician's decision that the patient's incapacity to manage his/her property must continue;
- a physician's decision that the patient is incapable to consent to treatment for a mental disorder in circumstances set out in the Regulations under the Act;
- a determination that the patient is incapable of consenting to the collection, use or disclosure of personal health information in the circumstances set out in the Regulations under the Act;
- when a twelve to fifteen year old is admitted to a psychiatric facility as an informal patient, and every three months thereafter;
- before issuing or renewing a CTO, a physician must be satisfied that the person who will be subject to the CTO (and his/her SDM, if any) have consulted with a Rights Adviser and have been advised of their legal rights.

CTOs are the only circumstance in which rights advice may be provided in the community.

### *Process of Rights Advice*

When any of the above described rights advice situations occur, the physician is required under the law to notify the rights adviser. The rights adviser is required, in turn, to promptly meet with the patient, except in the case of CTOs where the rights adviser is not required to meet but simply to 'provide' rights advice. The rights adviser must explain to the patient the significance of the situation. The rights adviser discusses the options available to the patient, including his/her right to have the situation reviewed by the Consent and Capacity Board, if he/she disagrees with the physician's decision.

If the patient wishes to have a hearing before the Consent and Capacity Board, the rights adviser assists the patient to make the application, to obtain legal counsel if so requested, and to apply for Legal Aid if so requested.

The rights adviser provides information to patients in a neutral, non-judgmental manner. The rights adviser must not make decisions for patients but assists them in carrying out their decisions.

### *Qualifications of a Rights Adviser (Mental Health Act Reg. 741)*

Only persons who meet the following requirements may be designated to perform the functions of a rights adviser under the Act whether in a psychiatric facility or with respect to a person who is being considered for the issuance or renewal of a community treatment order:

1. The person must be knowledgeable about the rights to apply to the Board provided under the Act, the Health Care Consent Act, 1996 and the Personal Health Information Protection Act, 2004.
2. The person must be knowledgeable about the workings of the Board, how to contact the Board and how to make applications to the Board.
3. The person must be knowledgeable about how to obtain legal services.
4. The person must have the communications skills necessary to perform effectively the functions of a rights adviser under the Act.
5. The person must have successfully completed a training course for rights advisers approved by the Minister and have been certified as having completed such a course. O. Reg. 616/00, s. 11; O. Reg. 331/04, s. 5.