



Psychiatric Patient Advocate Office

*Submission Regarding
Bill 77: Services for Persons with
Developmental Disabilities Act, 2008*

August, 2008

Psychiatric Patient Advocate Office
55 St. Clair Avenue West
Suite 802, Box 28
Toronto, ON, M4V 2Y7
Telephone: (416) 327-7000
Toll Free: 1-800-578-2343
www.ppao.gov.on.ca

PROMOTING PATIENTS' RIGHTS



Psychiatric Patient Advocate Office

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

August 12, 2008

Dr. Shafiq Qaadri
Chair
Standing Committee on Social Policy
Room 1405, Whitney Block
Queen's Park
Toronto, Ontario
M7A 1A2

Dear Dr. Qaadri:

Bill 77 – Services for Persons with Developmental Disabilities Act, 2008

Thank you for the opportunity to participate in the consultation process on Bill 77, Services for Persons with Developmental Disabilities Act, 2008. We believe that our submission and corresponding recommendations will strengthen Bill 77, and truly provide rights protection for some of the most vulnerable Ontarians, those with developmental disabilities.

This Bill must be clear, transparent and inclusive in its intent, purpose and scope while creating opportunities for individuals with a developmental disability to live in accepting, supportive and inclusive communities where they can realize their full potential, and where the contribution of all citizens is recognized and appreciated. This Bill must set the tone, the expectations, values, goals, philosophy and articulate the vision that the government has for Ontario. Bill 77 should provide the legal framework within which we as a society can not only support but embrace individuals with a developmental disability as they strive to be full participants in the community. Our recommendations will go a long way in protecting the legal, civil and human rights of individuals with a developmental disability.

Please contact me at (416) 327-7007 or David Simpson, Program Manager at (416) 327-7004, should you need additional information regarding this submission, or if we may be of further assistance in this critical undertaking.

Sincerely,

Vahe Kehyayan
Director

SUMMARY OF RECOMMENDATIONS

Preamble

Recommendation:

- The PPAO recommends that Bill 77 include a preamble that sets the expectations, values, goals and philosophy, and articulates the vision that the government has for Ontario and how we will support and indeed embrace individuals with a developmental disability as they strive to be full participants in the community.

Definition of Developmental Disability

Recommendation:

- The PPAO recommends that the Act have a more inclusive and comprehensive definition of “developmental disability” to specifically include those individuals with a “dual diagnosis”.

A Bill of Rights

Recommendations:

- The PPAO recommends that Bill 77 include a Bill of Rights to inform individuals of their rights under the legislation and to enhance the accountability and transparency while protecting the rights of the individual receiving services in the developmental sector.
- The PPAO recommends that the role of an independent advocate be enshrined in the Bill of Rights, by defining their role, function, mandate and legislated authority.

An Independent Advocate

Recommendations:

- The PPAO recommends that the Bill 77 enshrine in law the role of an independent advocate to assist and support the individual with a developmental disability and their families.
- The PPAO recommends that the government consider the PPAO’s model for the delivery of independent advocacy service and enshrined the role and function of an independent advocate in the legislation with the corresponding legal authority and mandate to protect individuals with a developmental disability.

Rights Advice – Consent and Capacity Issues

Recommendation:

- The PPAO recommends that the government include in Bill 77 provisions for mandatory and formal rights advice when individuals with a developmental disability or dual diagnosis are found either financially incapable or incapable of consenting to their own treatment.

Qualified Practitioners

Recommendations:

- The PPAO recommends that the government of Ontario consult and collaborate with stakeholders, families, providers, and the clients themselves when developing any regulation to “prescribe” the qualification of those who will work in and provide service in this sector.
- The PPAO recommends that the government broaden and enhance the definition of professional and specialized services so that it is more comprehensive and inclusive of all health, mental health and community services required by people with developmental disabilities or a dual diagnosis.

Access to Mental Health Services

Recommendation:

- The PPAO recommends that individuals with a developmental disability have access to a full range of mental health services and supports including: assessment, referral, treatment, counselling, crisis-intervention services, and case-management supports and that access to these services be enshrined in the Act

Support for Families

Recommendations:

- The PPAO recommends that the government of Ontario recognize the role that families play in the provision of care, support and services to individuals with a developmental disability.
- The PPAO recommends that the government establish a Family Advisory Committee with broad representation that reflects the diversity of Ontario.
- The PPAO recommends that the government review Ontario Disability Support Plan (ODSP) policy and immediately end the reduction of benefits to those individuals who remain living with a family member.

- The PPAO recommends that the government enshrine in law a Family Bill of Rights as a way to increase the accountability and transparency of those providing services to their loved one. Families must also have access to and the ability to make third party complaints to an independent advocate that is a partisan advocate for the individual with a developmental disability

Advisory Committee

Recommendations:

- The PPAO recommends that the government establish, in law, an advisory committee that could monitor, assess and evaluate the implementation of Bill 77 and the impact that it is having on the delivery and provision of services to people with a developmental disability.
- The PPAO recommends that the Advisory Committee have broad representation from all sectors of the developmental sector, the mental health sector and include clients, families, service providers, advocates and other interested parties.

Submission of the Psychiatric Patient Advocate Office

Bill 77: Services for Persons with Developmental Disabilities Act, 2008

Introduction

The Psychiatric Patient Advocate Office (PPAO) was established in 1983 as an arm's length program of the Ministry of Health and Long-Term Care to protect the legal and civil rights of inpatients in the current and divested provincial psychiatric hospitals. The PPAO also provides rights advice services to individuals living in the community and being considered for the issuance or renewal of a community treatment order (CTO), and their substitute decision-maker, if any, and to patients in Schedule 1 hospitals where the PPAO has been designated as "rights adviser."

The PPAO provides independent and confidential advocacy (instructed, non-instructed and systemic), rights advice and education. Using information, education, and referrals, we support self-advocacy and promote self-determination by working to empower mental health consumers to make informed decisions. Our vision is that persons with mental illness in Ontario will be treated with dignity and respect, that their legislated rights and entitlements are upheld at all times, and that they are actively involved in decisions affecting their life, care, and treatment. The PPAO provides services to individuals with a developmental disability and mental illness, often referred to as a "dual diagnosis." It is from this vantage point and experience that we comment on Bill 77.

In 2007, the PPAO addressed 4,140 individual advocacy issues; these included 1,250 therapeutic issues, 842 social issues and 2,048 legal issues. In 2007, the PPAO also received 6,884 requests for rights advice in nine tertiary care psychiatric facilities and one remaining provincial psychiatric hospital. In the same year, the PPAO's Community-based Rights Advice Program received 16,254 requests for rights advice. The PPAO provided services in 45 languages. In 2008, the PPAO celebrated its 25th anniversary of service provision to the people of Ontario.

A Preamble

Many individuals with a developmental disability are vulnerable because of their disability, their life circumstances, their inability to access services and supports, imperfect knowledge of their rights or uncertainty in where to turn for help. The intersection of each of these challenges magnifies the vulnerability, marginalization, and disenfranchisement of this group, and contributes to a dependency on others rather than independence and full participation as equal citizens. A preamble to Bill 77 would declare the objective and intent in proceeding with this legislation and frame the values, goals and philosophy, important to the generous interpretation

of an Act designed to improve the quality of care and life of individuals with a developmental disability. The Bill fails to address the stigma, discrimination and human rights violations experienced by this population, and does not address how it will create opportunities for individuals with a developmental disability to live in accepting, supportive and inclusive communities where they can realize their full potential and where the contribution of all citizens is recognized and appreciated. Lacking a preamble to guide its intent and overall scheme, the ameliorative qualities of the Bill might suffer a restrictive interpretation incapable of addressing the intersectional entrenchment of discriminatory attitudes and practices.

The PPAO recommends that Bill 77 contain a preamble to clearly declare the intent of this legislation, including: how it will improve the quality of life of individuals with a developmental disability or a dual diagnosis; the “service guarantees” they should expect; service standards and outcomes that are evidence-based best practices; how their legal and civil rights will be protected and promoted; what transparent complaint process will be available; the clear definition of eligibility standards, process and appeal opportunities; and how they can access independent advocacy should they require the services of such an advocate.

Recommendations

- The PPAO recommends that Bill 77 include a preamble that sets the expectations, values, goals and philosophy, and articulates the vision that the government has for Ontario and how we will support and indeed embrace individuals with a developmental disability as they strive to be full participants in the community.

Definition of Developmental Disability

The definition of “developmental disability” contained in Section 3 of Bill 77 is very narrow and restrictive in its scope. Many individuals with a developmental disability also have what we refer to as a “dual diagnosis,” meaning both a developmental disability and a mental illness. All too often such individuals find it particularly to access a full range of services and supports because service providers can’t decide which government program, that is, the mental health sector or the developmental sector, should be responsible for providing services. This causes many clients to fall through the cracks and their unique and special needs go unmet. At times it means that individuals are shuttled between the two systems, losing access to continuity of care and seamless service delivery from both systems and undermining a wholistic approach to care, treatment and quality of life while having all their needs addressed. The Act must clearly define “dual diagnosis” and must specifically include individuals with a dual diagnosis in the definition of developmental disability as contained in this legislation.

Recommendation:

- The PPAO recommends that the Act have a more inclusive and comprehensive definition of “developmental disability” to specifically include those individuals with a “dual diagnosis”.

A Bill of Rights

As a rights protection agency, the PPAO believes that the particular vulnerability and difference of individuals with a developmental disability or a dual diagnosis necessitates the establishment of a Bill of Rights in the law. Such a Bill of Rights could be developed in consultation and collaboration with all stakeholders, including clients, and it should clearly articulate the rights and entitlements of the individual and the services and supports they are entitled to receive under Bill 77. This would assist the government in heightening accountability and transparency while clearly defining in law the services, supports, conditions and quality of service that the individual could expect to receive.

Recommendations:

- The PPAO recommends that Bill 77 include a Bill of Rights to inform individuals of their rights under the legislation and to enhance the accountability and transparency while protecting the rights of the individual receiving services in the developmental sector.
- The PPAO recommends that the role of an independent advocate be enshrined in the Bill of Rights, by defining their role, function, mandate and legislated authority.

An Independent Advocate

The PPAO is of the view that many individuals with a dual diagnosis or developmental disability are vulnerable and require support to protect and promote the realization of their rights. It is imperative that the legislation enshrine in law a role for an independent advocate to assist and support the individual with a developmental disability and their families. The independent advocate would be a partisan and supportive advocate for the individual who had their own voice. If the individual had no voice, the advocate would become their voice. An advocate must be independent and free of real or perceived conflict of interest, if they are to be a partisan advocate charged with the responsibility of protecting the rights of some of the most vulnerable Ontarians amongst us. The Bill must explicitly state that the independent advocate cannot be a service provider within the developmental sector, but must be arms length to remove any of the concerns about bias, conflict of interest or having a vested interest in the outcome.

For the past quarter century, the PPAO has fulfilled this role within the mental health sector in Ontario, and it has become one of the most important checks and balances within this sector. The PPAO has also, through its individual case advocacy and systemic advocacy initiatives, helped shape the mental health sector, brought about systemic change, and protected and promoted the rights and entitlements of the people it serves. The PPAO is a service provider in almost every community in Ontario and the model for the delivery of independent advocacy service should be considered and enshrined in this legislation.

Recommendations:

- The PPAO recommends that the Bill 77 enshrine in law the role of an independent advocate to assist and support the individual with a developmental disability and their families.
- The PPAO recommends that the government consider the PPAO's model for the delivery of independent advocacy service and enshrined the role and function of an independent advocate in the legislation with the corresponding legal authority and mandate to protect individuals with a developmental disability.

Rights Advice – Consent and Capacity Issues

Individuals with a developmental disability are often incapable of consenting to treatment or incapable to manage their property. Often there is no formal “finding” by a qualified health practitioner and at times, there are “informal trusteeships” established to manage the individuals’ money or consent to their treatment. The PPAO is concerned that these practices are outside the law, and increase the vulnerability and marginalization of this client group. As a rights protection agency, we believe that formal, mandatory and independent rights advice must be provided to all individuals when such a finding is made, regardless of where or from whom they receive their care and treatment. It is advisable that rights advice become mandatory in these two situations when an individual with a developmental disability is in a residential setting, a government institution, or other care facility. As a best practice, the government should consider rights advice as an imperative and integral component of care and treatment and make it mandatory in every setting when such a finding is made. The PPAO has been providing rights advice in the mental health sector for more than two decades and it has become an important check and balance within that sector when protecting and promoting the rights of vulnerable Ontarians.

Recommendation:

- The PPAO recommends that the government include in Bill 77 provisions for mandatory and formal rights advice when individuals with a developmental disability or dual

diagnosis are found either financially incapable or incapable of consenting to their own treatment.

Qualified Practitioners

Individuals with a developmental disability or dual diagnosis should be entitled to receive services and supports from qualified professionals who have received specialized training and education. Receiving care, treatment, support and services from qualified professionals will address quality of care issues. A complaints procedure must be established to cover complaints against caregivers even if they are not members of a professional college. This will allow clients and families to hold people accountable when there is a complaint about the services provided by that individual or where their vulnerability has been exploited by their care provider.

The government of Ontario should work with stakeholders, families, providers, and the clients themselves when developing any regulation to “prescribe” the qualification of those who will work and provide services in this sector. It is also necessary for the government to broaden and enhance the definition of professional and specialized services so that it is more comprehensive.

Recommendations:

- The PPAO recommends that the government of Ontario consult and collaborate with stakeholders, families, providers, and the clients themselves when developing any regulation to “prescribe” the qualification of those who will work in and provide service in this sector.
- The PPAO recommends that the government broaden and enhance the definition of professional and specialized services so that it is more comprehensive and inclusive of all health, mental health and community services required by people with developmental disabilities or a dual diagnosis.

Access to Mental Health Services

Individuals with a developmental disability must have access to a full range of mental health services and supports including: assessment, referral, treatment, counselling, crisis-intervention services, and case-management supports, without fear of losing their home or placement within the developmental sector. All too often, individuals with a developmental disability that require hospitalization because of a mental illness, find it difficult to return to the placement from which they came. Often providers will cite that they lack the expertise to deal with the mental health issues and state that their placement is “no longer suitable” for the person because of their specialized needs. Mobile assessment, treatment and support team should be made available within the developmental sector as a way to ensure that individuals can have their mental health

needs met without fear of having to sacrifice their home, their friends and their supports. If mobile mental health services were available then the services could go to the individual instead of the individual having to be uprooted from their home and sent to another institution for assessment, care and treatment.

This Bill should also specifically define “treatment” so that all providers, clients and families are aware of the care and treatment that they are entitled to receive. A definition of treatment should be broad, inclusive, and developed in consultation with stakeholders and families. For example, “treatment” in the context of this Bill could include assessment, referral, treatment, counselling, crisis-intervention services, and case-management supports in addition to the definition enshrined in the Health Care Consent Act.

Recommendation:

- The PPAO recommends that individuals with a developmental disability have access to a full range of mental health services and supports including: assessment, referral, treatment, counselling, crisis-intervention services, and case-management supports and that access to these services be enshrined in the Act.

Support for Families

In Ontario many parents have chosen to keep their children with developmental disabilities at home and out of institutional care believing that this would provide an enhanced quality of life and more opportunities for their children. However, many of these parents are aging and the burden of providing care, often around the clock, is taking its toll on their health and well-being. Many worry about their children (who now may be adult themselves) and what will happen to them when they are gone. Many are not connected to formal services and supports within the developmental sector and the lack of housing options for their adult children means that they have few placement options. Families want and need emotional and financial support when choosing the option to have their loved one remain at home with them. Government policy now means that if they continue to have their adult children remain at home with them then the Ontario Disability Support Plan (ODSP) benefits are reduced by a couple of hundred of dollars per month. This appears as a “financial penalty” for those who have chosen home care instead of institutionalized care. Policies such as these need to be reviewed and revoked as they are potentially unfair and discriminatory. Families that choose to keep their loved on at home should not be financially penalized for doing so.

The PPAO believes that Bill 77 needs to address the needs of families and enshrine in law the entitlements, supports and services that they should receive. Perhaps a provincial Family Advisory Committee and a Family Bill of Rights could be established, in law, to ensure that the voice and issues of families are raised with decision makers, who can immediately address these issues and bring them to resolution. The Family Advisory Committee could act as an adviser to

both the Minister and Premier on family issues and the services and supports enshrined in Bill 77. All too often it is the family that provides the majority of supports and services to the individuals with a developmental disability and this contribution to the provision of care, support and services and the role that families play must be recognized by Bill 77.

Recommendations:

- The PPAO recommends that the government of Ontario recognize the role that families play in the provision of care, support and services to individuals with a developmental disability.
- The PPAO recommends that the government establish a Family Advisory Committee with broad representation that reflects the diversity of Ontario.
- The PPAO recommends that the government review Ontario Disability Support Plan (ODSP) policy and immediately end the reduction of benefits to those individuals who remain living with a family member.
- The PPAO recommends that the government enshrine in law a Family Bill of Rights as a way to increase the accountability and transparency of those providing services to their loved one. Families must also have access to and the ability to make third party complaints to an independent advocate that is a partisan advocate for the individual with a developmental disability.

Advisory Committee

The PPAO urges the government to establish, in law, an advisory committee that could monitor, assess and evaluate the implementation of Bill 77 and the impact that it is having on the delivery and provision of services to people with a developmental disability. The Committee could advise the government on the status of the implementation, make recommendations on systemic changes and advocate for improvements to the legislation over time and through implementation. Such a Committee would increase accountability, transparency, reporting and serve as an additional protection for individuals with a developmental disability while playing an advisory role to both the Minister and the Premier on disability issues. This would increase public confidence in a system that is intended to protect vulnerable children and adults.

Recommendations:

- The PPAO recommends that the government establish, in law, an advisory committee that could monitor, assess and evaluate the implementation of Bill 77 and the impact that it is having on the delivery and provision of services to people with a developmental disability.

- The PPAO recommends that the Advisory Committee have broad representation from all sectors of the developmental sector, the mental health sector and include clients, families, service providers, advocates and other interested parties.

Conclusion

The PPAO believes that if our recommendations are considered and enshrined in this Bill, that it will be a stronger piece of legislation and provide further protection to some of the most vulnerable Ontarians amongst us, those with a dual diagnosis or developmental disability. We all have an obligation to protect vulnerable children and adults and this Act should provide that protection will address quality of care and life issues, ensuring greater access to services and supports, providing a guarantee that service will be provided by qualified professionals, adopting strategies to combat stigma and discrimination and by protecting and promoting the rights and entitlements of all individuals with a developmental disability.

Only when we include these provisions in the law can we reduce vulnerability and increase quality of life, create greater access to opportunities that enrich their lives and support full participation in an accepting, supportive and inclusive community.