

**Dual Diagnosis
Implementation
Committee
of Toronto**

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**NATIONAL
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CHAPTER**
C/O Dual Diagnosis
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Centre for Addiction and
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Dr. Shafiq Qaadri
MPP, Etobicoke North
Chair, Standing Committee on Social Policy
Main Legislative Building
Toronto, ON
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August 11, 2008.

Dear Dr. Qaadri,

It was with pleasure that our joint group (the National Association for the Dually Diagnosed and the Dual Diagnosis Implementation Committee of Toronto) presented our review of *Bill 77: An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain statutes.*

Attached you find our formal written submission. As Bill 77 leaves much to subsequent regulation, the members of NADD Ontario and DDICT request involvement in this process.

We look forward to subsequent changes in the proposed legislation.

Respectfully submitted,

Mary Jane Cripps, Co-Chair
John Mohler, Co-Chair
The Dual Diagnosis Implementation
Committee of Toronto

A handwritten signature in black ink, appearing to read 'Susan Morris'.

Susan Morris, President
National Association for the
Dually Diagnosed – Ontario
Chapter
Board of Directors

cc. Katch Koch

SUBMISSION

Bill 77

An Act to provide services to persons with developmental disabilities, to repeal the Developmental Services Act and to amend certain statutes.

This submission is made on behalf of the National Association for the Dually Diagnosed – Ontario Chapter (NADD Ontario) and the Dual Diagnosis Implementation Committee of Toronto (DDICT).

NADD Ontario is a voluntary provincial association representing families and service providers who work in the health and developmental service sectors. We are concerned about the mental health of individuals with developmental disabilities. Our advocacy activities focus on service excellence through initiatives that support education and training directed to staff and families

The Dual Diagnosis Implementation Committee of Toronto monitors policy developments and work plans related to system design and implementation undertaken by the Ministry of Community and Social Services, the Ministry of Health and Long Term Care and the Community Network of Specialized Care (CNSC). The Committee also supports and encourages cross sector, system and service delivery integration at a local, regional and provincial level.

Dual diagnosis in Ontario refers to people who have both a developmental disability and mental health needs.

Given the mandate of these two organizations, our response is focused on ***how well Bill 77 will serve people with dual diagnosis.***

A summary of recommendations

- 1. Provide a preamble for Bill 77 and, given that over 1/3 of people with developmental disability also have mental health needs, it must include reference to individuals living with a dual diagnosis and/or challenging behaviour.**
- 2. NADD Ontario and the DDICT call for Bill 77 to include a Bill of Rights for individuals and families in the model of the Long Term Care Homes Act.**
- 3. An arms length provincial advocate's office must be established with the mandate of receiving and investigating complaints related to adults living with developmental disabilities and dual diagnosis, including possible rights violations and other complaints that may arise regarding the application, assessment and re-assessment process under the provisions of Bill 77.**
- 4. Throughout its provisions, where relevant, Bill 77 must reference the Personal Health Information Protection Act, the Health Care Consent Act and the Substitute Decisions Act and align itself with these Acts.**
- 5. NADD Ontario and the DDICT call for a legal review of the Personal Health Information Protection Act, the Health Care Consent Act and the Substitute Decisions Act to ensure that they specifically refer to individuals with developmental disabilities and dual diagnosis, their families/caregivers, and the organizations that serve them.**
- 6. The qualifications of persons conducting assessments and re-assessments, and the methods and criteria they employ must be spelled out in the legislation. In this regard NADD Ontario and DDICT, specifically with reference to Section 14(3) and Section 14(4) which pertain to diagnostic assessments, recommend that Bill 77 refer to the "person with the prescribed qualifications" as regulated professionals, qualified to determine a developmental disability.**
- 7. The definition of professional and specialized services must be broadened in the legislation to include not only those services that may be purchased but all those necessary health, mental health and community services required by people with developmental disabilities and dual diagnosis.**
- 8. NADD Ontario and DDICT support the recommendation from Community Living Ontario that states the following:**
 - a. In order to address potential conflicts within the application processes, and to build on effective processes currently being used, the legislation should make clear that various elements may be delivered by different bodies within a given region. The various bodies responsible for the administration of the application process must be connected in such a way as to ensure easy access for people applying for support while**

eliminating any potential for conflicts. To this end, the legislation should refer to an “application process” rather than application centres. The responsibility for allocations of funding should remain a direct responsibility of government.

- 9. Enshrine standardized principles in the legislation that support an improved access process based on fairness, equity and consistency.*
- 10. Bill 77 must fully outline a fair and impartial appeals process within its provisions.*
- 11. While NADD Ontario and DDICT fully support both direct and agency funding models, there must be attention paid to ensuring a stable system without the threat of eroding resources or quality of care.*
- 12. Quality of care, standards of service delivery, and accountability requirements need to be applied consistently across the different funding models.*
- 13. Independently funded planning supports to those who require such assistance must be made available.*
- 14. Bill 77 leaves much to subsequent regulation. Members of NADD Ontario and DDICT request involvement in this process.*

Dual Diagnosis

In Ontario, **38%** of individuals with a developmental disability have a dual diagnosis.¹ In terms of actual numbers, this means that, out of 304,007 Ontarians with a developmental disability, **115,522** have a dual diagnosis.²

People with dual diagnosis have complex needs that require service across sectors, including, but not limited to, developmental, health and mental health services.

This submission analyzes Bill 77 from the perspective of how well this legislation addresses the needs of individuals with a dual diagnosis and/or challenging behaviour.

Bill 77 is welcome

Bill 77 is a positive step forward because it is intended to address services for people with developmental disabilities in an environment of deinstitutionalization and an expansion of community living. It also seeks to provide individuals and families with more choice so that, through direct funding, for example, they can customize service plans in ways that most closely match needs.

Concerns re Bill 77 as currently written:

In focusing on administrative oversight of the system of services for people with developmental disabilities, Bill 77 misses some crucial issues, important both to people with developmental disabilities and dual diagnosis:

1. A preamble that offers the background, context and objectives of the legislation and includes reference to dual diagnosis.
2. Protection for and oversight of the rights of individuals and families/caregivers and a provision for recourse,
3. Reference to and protection for the health and mental health needs of people with developmental disabilities,
4. A clear specification of the qualifications of the professionals that will be providing assessments and re-assessments and an expanded definition of professional and specialized services,
5. A clear description of an application process rather than prescribing an application structure.
6. Direct and agency funding models that ensure program stability and protect against an erosion of capacity.

¹ Yu, D. & Atkinson, L. (1993, republished in 2006). Developmental disability with and without psychiatric involvement: prevalence estimates for Ontario. Journal on Developmental disabilities, Spring, p. 1 – 6

² Ibid

The concerns

1. A preamble that offers the background, context and objectives of the legislation and includes reference to dual diagnosis.

In the last decade there has been a lot of effort and consultation within the field of developmental disabilities in relation to system transformation, development of dual diagnosis policy guidelines and Specialized Networks for individuals with dual diagnosis and/or challenging behaviour. As a society, significant shifts have occurred in how individuals with disabilities are viewed as full citizens. There is a missed opportunity within Bill 77, as it is currently written, in that there is no context that describes its overall intent and objectives.

Recommendations:

- *Provide a preamble for Bill 77 and, given that over 1/3 of people with developmental disability also have mental health needs, it must include reference to dual diagnosis.*

2. Protection for and oversight of the rights of individuals and families/caregivers and a provision for recourse

The legislation expands choice for individuals and families but it also offers opportunities for potential incursion upon their rights.

People with developmental disabilities and, in particular, people with dual diagnosis, are among the most vulnerable, stigmatized and marginalized. They have the right to the same protections as any other citizen.

Bill 77 is weak on measures that protect the rights of individuals with developmental disabilities and dual diagnosis and their families/caregivers.

The Long Term Care Homes Act (2007), as an example, is extensively concerned with the protection of rights of vulnerable persons. It provides, within the legislation itself, a Residents' Bill of Rights (Part II: Residents' Rights, Care and Services) that specifically prescribes rights.

Also note the province's Child Advocate Office, constitutes recourse for children and youth with developmental disabilities, but is not available to adults.

Recommendations:

- *NADD Ontario and the DDICT call for Bill 77 to include a Bill of Rights for individuals and families in the model of the Long Term Care Homes Act.*
- *An arms length provincial advocate's office must be established with the mandate of receiving and investigating complaints related to adults living with developmental disabilities and dual diagnosis,*

including possible rights violations and other complaints that may arise regarding the application, assessment and re-assessment process under the provisions of Bill 77.

3. Reference to and protection for the health and mental health needs of people with developmental disabilities

There is no reference to how personal health information³ will be protected or how consent and capacity issues for treatment and finance will be handled. It is the policy of the Ontario government that individuals with a dual diagnosis receive care and treatment from health and developmental service providers (as outlined in the Interministerial Joint Guidelines for Persons with a Dual Diagnosis, 1997, and currently being revised). The implementation of this policy along with the increased demand for medical care from the generic health system as institutions have closed, have resulted in numerous examples of the inappropriate release of health information and application of consent by both health care and developmental service providers as it pertains to treatment and financial decision making. The cause of this appears to be lack of knowledge that such laws exist, or that they apply to this population.

However, as an illustrative example, the Long Term Care Homes Act makes frequent reference to the Personal Health Information Protection Act (PHIPA), the Health Care Consent Act and the Substitute Decisions Act, ensuring that it is aligned with these important legislated provisions and protections.

Cases in point:

- The proposed Application Centres and many existing developmental services would be deemed *health information recipients* under the Personal Health Information Protection Act and subject to restrictions as outlined under Part IV Collection, Use and Disclosure (49). Bill 77 is silent on their obligations under PHIPA and this is unacceptable. As a further point, Bill 77 gives sweeping powers for Ministry staff to demand to see records [Part VII 4(e)]. Access, without consent, would inevitably include the right to see personal information, and personal *health* information. These powers violate privacy. People with developmental disabilities and dual diagnosis have a right to expect the same safeguards to their privacy as other citizens. The powers of Ministerial administrative scrutiny in Bill 77 must be prescribed and/or limited so that privacy violations do not occur. Access to personal health information must be accompanied by consent.
- Bill 77 provides for direct funding to go to "another person acting on behalf of a person with a developmental disability" [Part IV 11 (2)]. The legislation is silent on the legal standing of both the individual and "another person." The Health Care Consent Act demands that "another person" can make financial

³ The Personal Health Information Protection Act (PHIPA) defines personal health information as meaning identifying information about an individual in oral or recorded form, if the information, (a) relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family, (b) relates to the providing of health care to the individual, including the identification of a person as a provider of health care to the individual, (c) is a plan of service within the meaning of the *Long-Term Care Act, 1994* for the individual.

decisions on behalf of an adult 18 years or older only if he or she has been deemed incapable. In order to assess capacity, individuals must undergo a formal capacity assessment. If found incapable for financial decisions, a substitute decision maker is appointed with Power of Attorney to act on the individual's behalf. This provision also applies to family members of adults 18 years or over. In terms of Bill 77, this would mean that only the individual, him or herself, if capable, could disperse funds. If deemed incapable, a designated substitute decision maker is the only legally designated person able to receive direct funding and make decisions regarding how it is dispersed.

- Bill 77 makes no provisions for recourse if, indeed, rights have been violated.

It is unacceptable that individuals with developmental disabilities and dual diagnosis, and their families do not have the same rights protection as other vulnerable groups in Ontario.

Recommendations:

- *Throughout its provisions, where relevant, Bill 77 must reference the Personal Health Information Protection Act, the Health Care Consent Act and the Substitute Decisions Act and align itself with these Acts.*
- *NADD Ontario and the DDICT call for a legal review of the Personal Health Information Protection Act, the Health Care Consent Act and the Substitute Decisions Act to ensure that they specifically refer to individuals with developmental disabilities and dual diagnosis, their families/caregivers, and the organizations that serve them.*

4. A clear specification of the qualifications of the professionals that will be providing assessments and re-assessments and an expanded definition of professional and specialized services

Throughout the legislation, “prescribed” is used with frequency. For example, in relation to administrative requirements:

“prescribed” type of services (pg i and elsewhere)
“prescribed” quality assurance measures (pg i and elsewhere)
comply with reporting requirement as “prescribed” (pg 9)
financial records will be made available in the “prescribed” manner (pg 22)

Bill 77 defines “prescribed” as meaning prescribed by regulation [Part I 4(2)].

Thus, many important details of how Bill 77 will actually operate in the real world are unknown and will have to be specified in regulations and/or policy.

A particular problem is the stipulation that ***applicants will be assessed by persons with “prescribed” qualifications [Part V 14 (3)] using methods of assessment or criteria as may be “prescribed” [Part V 14(3)].***

The qualifications of persons conducting assessments and re-assessments, and the methods and criteria they employ are of immense concern to families and to the professionals and para-professionals that provide service to individuals with developmental disabilities and/or dual diagnosis.

In addition, the definition of professional and specialized services is too narrow [Part I 4(2)]. It neglects the full range of professionals and para-professionals within the health and developmental sectors, required to provide services under Bill 77 and the breadth of services currently provided to individuals with developmental disabilities and/or dual diagnosis. For example, both NADD Ontario and the DDICT represent specialized programs, some of which are funded by MCSS that support individuals with a dual diagnosis. MCSS and MOHLTC funded services include mental health and justice services, day treatment, case management, Assertive Community Treatment, housing and support to housing.

Recommendations:

- ***The qualifications of persons conducting assessments and re-assessments, and the methods and criteria they employ must be spelled out in the legislation. In this regard NADD Ontario and DDICT, specifically with reference to Section 14(3) and Section 14(4) which pertain to diagnostic assessments, recommend that Bill 77 refer to the “person with the prescribed qualifications” as regulated professionals, qualified to determine a developmental disability.***
- ***The definition of professional and specialized services must be broadened in the legislation to include not only those services that may be purchased but all those necessary health, mental health and community services required by people with developmental disabilities and dual diagnosis.***

5. A clear description of an application process rather than prescribing an application structure.

People with developmental disabilities and their families need a transparent application process that is, and is seen to be, fair, consistent and accessible.

Application centres may constitute a barrier to access and an unwanted bottleneck for individuals with more complex needs such as dual diagnosis, who often enter the system through services and supports funded by other ministries, as noted above. We would not want the Act to put in place unnecessary steps that would impede appropriate individuals from acquiring the necessary specialized services outside of the developmental disability sector.

Further, people with dual diagnosis have needs that fluctuate significantly and rapidly. They will not be well served by a process that is unable to shift, in tandem with their needs and within reasonable time frames. For example, the application centres, as presently conceived have no provisions for connections to the Specialized Networks that have been established by MCSS to serve individuals with a dual diagnosis.

Recommendations:

- ***NADD Ontario and DDICT support the recommendation from Community Living Ontario that states the following:***
 - ***In order to address potential conflicts within the application processes, and to build on effective processes currently being used, the legislation should make clear that various elements may be delivered by different bodies within a given region. The various bodies responsible for the administration of the application process must be connected in such a way as to ensure easy access for people applying for support while eliminating any potential for conflicts. To this end, the legislation should refer to an “application process” rather than application centres. The responsibility for allocations of funding should remain a direct responsibility of government.***
- ***Enshrine standardized principles in the legislation that support an improved access process based on fairness, equity and consistency.***
- ***Bill 77 must fully outline a fair and impartial appeals process within its provisions.***

6. Direct and agency funding models that ensure program stability and protect against an erosion of capacity.

The legislation provides for portable funding in that those granted direct funding (either individuals or a person acting on their behalf) may purchase services [Part IV 11(2)]. With regard to meeting the specialized needs of individuals with a dual diagnosis and/or challenging behaviours, establishing and maintaining quality services based in best practice that include cross sector inter-professional approaches, requires a stable funding context. As the Act provides for reassessments, and for subsequent alterations in the planned service profiles [Part V 20 a & b], there is the possibility that some clients may lose their designation and funding, or their service profile may be so altered that a different set of services are now required.

This potential funding instability makes long term human resource planning difficult, and can undermine the clinical and administrative infrastructure required to support specialized care. Additionally, when the direct funding model is applied to accessing specialized resources through a purchase of service model, there can be unintended consequences. For example fragmented care can result in situations where direct funding does not pay for the time required to support the purchased resource to participate in an interprofessional, cross sector team approach. Additionally

specialized service agencies currently find it difficult to attract scarce specialists who prefer working in a private practice model.

Of special note, some families (especially those with loved ones who have complex needs) will need assistance planning for the expenditure of direct funding. These services must be funded and made available to them.

Recommendations:

- ***While NADD Ontario and DDICT fully support both direct and agency funding models, there must be attention paid to ensuring a stable system without the threat of eroding access to resources or quality of care.***
- ***Quality of care, standards of service delivery, and accountability requirements need to be applied consistently across the different funding models.***
- ***Independently funded planning supports to those who require such assistance must be made available.***

7. A final recommendation

- ***Bill 77 leaves much to subsequent regulation. Members of NADD Ontario and DDICT request involvement in this process.***

Respectfully submitted,

Mary Jane Cripps, Co-Chair
John Mohler, Co-Chair
The Dual Diagnosis Implementation Committee of Toronto

Susan Morris, PresidentChair
Board of Directors
National Association for the Dually Diagnosed – Ontario Chapter