



Dual Diagnosis Position Paper

Prepared by
National Coalition on Dual Diagnosis



Developmental Disabilities Section of the
Canadian Psychiatric Association



NADD Ontario

Dual Diagnosis Position Paper

Dual Diagnosis: Coping with mental health problems when you have a developmental disability.

A National Coalition on Dual Diagnosis

In May 2008, a **national coalition** of individuals, families and representatives from organizations was formed. The sponsoring organizations include:

Canadian Association for Research and Education in Intellectual Disabilities (CARE – ID)/ Association canadienne pour la recherche et l'enseignement en déficience intellectuelle (ACREDI): represents researchers, educators, clinicians, care providers, and other persons with an interest in intellectual disabilities. Provides a national voice and resource, promoting research and education in intellectual disabilities. See: <http://www.care-id.com/>

National Association for the Dually Diagnosed – Ontario Chapter (NADD - Ontario): A voluntary provincial association representing families and service providers who work in the health and developmental service sectors and is concerned about the mental health of individuals with developmental disabilities. NADD Ontario's advocacy activities focus on service excellence through initiatives that support education and training directed to staff and families. See: <http://www.naddontario.org/>

Developmental Disabilities section of the Canadian Psychiatric Association (CPA): This sub-section of the CPA was established in 2007. It aims to raise the profile of developmental disability (DD) within Canadian psychiatry and to establish a network of psychiatrists working in this field in Canada. Its goals for 2008 are to liaise with the Mental Health Commission of Canada; put together a theme journal on Developmental Disabilities in the Canadian Journal of Psychiatry; and to present a symposium at the Annual CPA Conference on DD.

Dual Diagnosis Program, Centre for Addiction and Mental Health: A specialized program serving people with dual diagnosis and their families through community based Interprofessional teams, a day treatment service and an inpatient unit serving Toronto and Peel regions. See: http://www.camh.net/Care_Treatment/Program_Descriptions/Mental_Health_Programs/Dual_Diagnosis/index.html

See Appendix 1 for the full membership list.

What is Dual Diagnosis?

There is a confusion of terms in Canada and other jurisdictions. In many parts of Canada and internationally, dual diagnosis refers to people who have a mental illness and an addiction (sometimes called a concurrent disorder). However, in Ontario and several other provinces, people living with lifelong developmental disabilities and mental health needs are said to have a dual diagnosis.

In Canada, 38% of people with a developmental disability also have a mental illness. This means that there are approximately 380,000 individuals with a dual diagnosis.¹

Purpose of this document

People with dual diagnosis have many champions throughout Canada but they have not previously come together to develop a clear set of agreed upon national recommendations on what would most effectively help the dually diagnosed and their families. This document was developed through the expertise of broad group of experts who formed a National Coalition for Dual Diagnosis. This paper states:

The needs of persons with dual diagnosis	page 5
Explanations for why these needs are not met	page 5
The problems we must solve	page 7
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Values statement

People with a dual diagnosis are particularly vulnerable, stigmatized and marginalized. They have a right to equal access to effective and adequate health care and other services that ensure **health equity**.*

* **Health equity** does not necessarily mean equal outcomes. Many people with a dual diagnosis are misunderstood, cannot communicate, or are denied certain services. They may have access to some services, but outcomes will be poor unless services are designed to meet their particular needs.

Health inequities among people with a dual diagnosis:

People with a dual diagnosis:

- Have complex needs and find themselves entangled in multiple systems of assessment and management, often unconnected from one another.
- Have inadequate access to the positive determinants of health (education, housing, nutrition, economic security, work, safe communities and social inclusion).

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

- Estimates of people with dual diagnosis among the homeless or inadequately housed range from 10 – 15%² up to 40 – 50%.³
- Experience the “double jeopardy” effect of stigma which occurs when two disabilities (developmental and mental health needs) are present in the same person, further marginalizing and disadvantaging them. The result is often “diagnostic overshadowing,”⁴ meaning that mental health problems are ignored and untreated because the symptoms are judged to be “just” part of the developmental disability.
- Are more likely than their non-disabled peers to have challenging behaviours⁵ defined as aggression, self-injury, and destructive, disruptive or non-compliant behaviours.⁶ These behaviours further marginalize and isolate them.
- Finally, experience a common system response, which is to medicate them with psychotropic medication to “treat” behaviour problems. Half of adults with developmental disabilities living in the community are prescribed psychotropic medication.⁷ These medications can be ineffective when they are prescribed without an in-depth assessment of the basis for the client’s challenging behaviours.⁸

These factors combine to create extreme health inequities.

² Personal communication (July, 2008). Donna Lougheed, Psychiatrist, Faculty of Medicine, University of Ottawa.

³ Personal communication (May, 2008). Developmental Pediatrician (Chris Loock, MD) working in Vancouver regarding her own research.

⁴ Reiss, S. & Szyszko, J. (1983). Diagnostic overshadowing and professional experience with mentally retarded persons. American Journal of Mental Deficiency, 87, p. 396 – 402.

⁵ Whitaker, S. & Read, S. (2006). The prevalence of psychiatric disorders among people with intellectual disabilities: An analysis of the literature. Journal of Applied Research in Intellectual Disabilities, Vol 19, p. 330 – 345.

⁶ Lowe, K. Allen, D. Jones, E. Brophy, S. Moore, K. & James, W. (2007). Challenging behaviours: prevalence and topographies. Journal of Intellectual Disability Research, 51:8, 625-636.

⁷ Lunskey, Y. Emery, C. & Benson, B. (2002). Staff and self-reports of health behaviours, somatic complaints and medications among adults with mild intellectual disability. Journal of Intellectual Disability, 27(2), p. 125 - 153.

⁸ Clarifying comment from Bruce McCreary, MD, FRCPC regarding findings as published in Tyrer, P. Oliver-Africano, P. C. & Ahmend, Z. et al (2008). Respiridone, haloperidol and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: A randomized control trial. Lancet, Vol 371, p. 57 – 63.

What do people with a dual diagnosis need?

They need what everyone else needs:

- Welcoming communities that include them as equal citizens.
- Places to live that are safe and affordable along with flexible supports. These services must be available for as long as they are needed.
- The love and support of family and friends. Some have this but many are all alone.
- Access to paid-if-necessary advocates for individuals who are alone and unsupported and for families that have difficulty navigating services.
- Education, health, community and developmental services that can respond appropriately, effectively and adequately to the ***complexity*** of their situation.
- Access to primary care – typically defined as a family physician or nurse practitioner.

Why don't they get these things?

Is it because education, health, community and developmental service professionals and para-professionals are not trained to help people with complex and chronic problems?

Is it because the different service sectors do not work well together?

Is it because there is no unifying policy and the different levels of government who fund these services are isolated from one another?

Is it because there is confusion regarding federal versus provincial health care jurisdictions – particularly in regard to First Nations peoples?

Is it because society doesn't know and doesn't understand – and therefore is unable to help?

Perhaps it is all of these things.

The human and economic costs

Our education, health, community and developmental service systems struggle to serve people who have complex and multiple problems. This inadequacy is costly in both human and economic terms.

The human cost

People with a dual diagnosis...

- Have complicated medical and psychiatric needs, yet are bounced from one service to another – with many not understanding or helping them;
- Can be over-medicated and live a half-life, because they are “better managed that way”;
- Can be left without support to help them manage life in the community and, as a result, come into contact with the law and end up in jail or on forensic units in psychiatric hospitals;
- Are often denied places in housing services because “their needs are too complicated.” Life on the streets for this extremely vulnerable group exposes them to exploitation and violence;
- Despite a formal policy of deinstitutionalization, the reality can, in fact, be that people become re-institutionalized – in jails, hospital wards and long term care facilities - because of huge service gaps;
- Some have been rejected by families - or have rejected their family - and are without any support. These are the people who are most vulnerable to homelessness;
- Families and caregivers often have to relocate to find services, yet our public health system guarantees portability.

In their turn, many families wanting to help are left without support. They are doing their best to cope with significant psychological and financial burdens.

The economic cost

People with a dual diagnosis can end up...

- Losing opportunities to be productive citizens because of system failures. There is also loss of family income and productivity as they care for a loved one with complex needs;
- Staying in hospital or a long term care institution much longer than they need because there is no place to go and few community supports and services to help them;
- With chronic medical and psychiatric problems because they were not caught earlier when they were easier to treat;
- With behaviours that are out of control because there is little help – and, families feel, no one cares.

Too often, they end up involuntarily and for reasons beyond their control, inappropriately institutionalized, in jail or find themselves on the street and subject to risks of violence and the physical, sexual or emotional abuse common in such environments.

What are the problems we must solve?

People with a dual diagnosis ***do not presently have timely or adequate access, across their lifespan*** to:

- ***Health promotion***: Equal access to the positive determinants of health, including active physical and mental health promotion, starting at birth.
- ***Disease prevention***: Appropriate, adequate and effective education, health, community and developmental services that prevent disease – whether physical or mental.
- ***Primary care***: Equitable access to primary care providers who have adequate training to respond to their complex problems and meet their needs. Also, recognition among primary care practitioners of the need among this group of patients for individualized attention and appropriate social supports.
- ***Specialized care***: Timely referral and access to specialized services.

Recommendations for change

A **national mental health strategy** that includes the following statement:

People with a dual diagnosis are particularly vulnerable, stigmatized and marginalized.

Nonetheless, they are citizens of this country, entitled to health equity and an equal opportunity to live and participate - with respect and dignity – when and how they choose - in Canada's communities

To achieve this goal, the following must be in place:

1. **Enabling government policies**

- a. ***National leadership, through Health Canada and the Mental Health Commission of Canada, is required to develop policies that can guide provincial and territorial governments*** in the delivery of mental health and health care services to people with a dual diagnosis.
- b. ***Provincial/territorial and regional*** policies must encourage inter-professional education, investment in inter-professional care teams and remove barriers to collaborative practice.
- c. ***Provincial/territorial and regional policies must also address the current silos between ministries governing developmental services and health.*** These two sectors often work under legislation and government policies that support them operating separately, without critical system and program level linkages necessary for effective, adequate and appropriate care and service for people with a dual diagnosis. Ministerial policies must support cooperation, starting at the top, so barriers to collaboration are removed and front-line services are required to work together.

2. Professional and para-professional preparedness through training and education

- a. Education, health, community and developmental service professionals and para-professionals must have ***undergraduate, post graduate and ongoing professional training*** so that they can respond effectively, adequately and appropriately to the complex needs of this group and their families. Universities and colleges must review all their curricula to ensure that the needs of people with developmental disabilities and dual diagnosis are considered. Learning programs should include ***anti-stigma training*** that addresses negative attitudes head on and instils new, more respectful behaviours.
- b. **Health professionals should have the choice of specialist training program options that focus on people with developmental disabilities and dual diagnosis.** At present, most universities and college programs do not have graduate programs that offer this choice leading to a shortage in much needed specialists.
- c. ***Professionals and para-professionals must train and work in collaborative care teams*** that bring together a variety of skills to address complex problems. Sufficient numbers of these teams ensure accessibility. Professional colleges and organizations also have to support collaborative care and develop standards of care for people with dual diagnosis.
- d. People with a dual diagnosis come into contact with ***emergency responders (ambulance staff, para-medics and fire fighters) as well as police and correctional staff.*** These professionals and para-professionals also require training in their basic programs so that they can understand the complex needs of this most vulnerable group.

3. Help for families, friends, and caregivers

- a. ***Families, friends, and caregivers must be included*** in all activities related to planning, designing and implementing policies and programs for their loved ones.
- b. ***Families, friends, and caregivers, themselves, need support and help.*** This involves access to their own physical and mental health care through education, support groups and respite care. It is important that these services are aligned with what families need and are flexible in their delivery. They also need a choice of meaningful day supports/programs for their loved ones that enhance their lives.
- c. ***Families, friends, and caregivers need to know that services for people with dual diagnosis are available and accessible close to home.*** It is unacceptable that families have had to relocate to find services or that their loved ones are sent away because necessary care does not exist in their own community. Families need better guarantees that services for people with a dual diagnosis are widely available, consistent and more accessible.

4. The need for accurate data and best practice research

- a. ***In Canada, there is a need to better support the accurate collection of comprehensive data on the prevalence rates of developmental disabilities in national population health studies. There are limited attempts to ascertain levels of specific disabilities and few studies on the impact of a dual diagnosis.*** This information is required to alert national, provincial, territorial and regional governments to the level of need among this vulnerable group. The Public Health Agency of Canada, the Institute for Clinical Evaluative Studies, the Canadian Institutes of Health Research and the Canadian Institute for Health Information must address this oversight.
- b. ***There is also a need for best practice, program evaluation, service system and policy research.*** The Canadian Institutes of Health Research and the Institute for Clinical Evaluative Sciences, particularly, could play a significant role in helping map out a research agenda for these populations.

The Mental Health Commission of Canada must include consideration of people with dual diagnosis in its homelessness and mental illness initiative. This group is represented among the homeless and cannot be neglected in the project that is about to be implemented in five Canadian cities. Estimates of people with dual diagnosis among the homeless or inadequately housed range from 10 – 15%⁹ up to 40 – 50%.¹⁰

Making these recommendations a reality

1. The formation of a national coalition that supports these recommendations:

As is so often the case, service providers, educators, clinicians, researchers and families have their hands full supporting a group whose needs are extensive and whose problems are so complex. This essential work leaves little time to ponder the bigger pictures of National leadership, social advocacy and targeted recommendations that, if implemented, would improve the quality of life for people with dual diagnosis. Bringing families, advocates, and organizations together to discuss shared problems and develop a consensus on solutions is a historical moment and an initiative that must be built upon. This has now begun with the coalition that includes the National Association of Dual Diagnosis – Ontario Chapter (NADD - Ontario), the Canadian Association for Research and Education in Intellectual Disabilities (CARE – ID), the Developmental Disabilities section of the Canadian Psychiatric Association, and the Dual Diagnosis Program, Centre for Addiction and Mental Health.

⁹ Personal communication (July, 2008). Donna Loughheed, Psychiatrist, Faculty of Medicine, University of Ottawa.

¹⁰ Personal communication (May, 2008). Developmental pediatrician (Chris Loock, MD) working in Vancouver regarding her own research.

2. Inter-professional education, collaborative mental health care and shared care:

These models are supported by federal funds and newer provincial strategies. They support the type of collaborative practice that is most helpful for people with dual diagnosis. The problem at present is that they are unevenly distributed with some provinces and territories far behind in adoption. Even where there is acknowledgment of the value of collaborative care, there are not enough teams deployed and there is no specific policy that ensures that these models include training for all health professionals on attitudinal acceptance and the skills to respond effectively to people with developmental disabilities.

3. Family advocacy:

The community living movement and now the mental health field has had the benefit of the power of family advocacy. Family voices have made a real difference. People with dual diagnosis have passionate family members who are beginning to mobilize to bring greater attention to the needs of their loved ones. Those professionals experienced in providing services further strengthen advocacy efforts for people with a dual diagnosis.

4. The Mental Health Commission of Canada (MHCC):

The MHCC is a particularly welcome addition to the national landscape for people with a dual diagnosis as they have long required a "home" where it is possible to bring the needs of this greatly marginalized group to broader attention. The Commission has the power and the capacity to secure a place for this particularly vulnerable population in its long-term structures and strategies.

Appendix 1

National Coalition Membership

Panel to develop policy statement

Chair:

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