



Centre for Addiction and Mental Health  
Centre de toxicomanie et de santé mentale  
Dual Diagnosis Program

## Dual Diagnosis Backgrounder

Prepared by  
National Coalition on Dual Diagnosis



Developmental Disabilities Section of the  
Canadian Psychiatric Association



NADD Ontario

## **Backgrounder**

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

### **Introduction**

The estimated prevalence rate of Canadian children and adults living with developmental disabilities is between 1 – 3% (up to 1 million Canadians).<sup>1</sup> This figure includes individuals with conditions such as Down Syndrome, Autism Spectrum Disorder, Fetal Alcohol Syndrome or brain injury (prior to age 18). Individuals with developmental disabilities also have higher rates of mental and physical illnesses than the average Canadian. At any time, approximately a third of our citizens with intellectual disabilities experience psychiatric difficulties (up to 380,000 Canadians).<sup>2</sup>

During the 1970s in Canada (as in other countries in the developed world), government policies were put in place whereby large institutions for people with developmental disabilities were closed down in favour of supporting these individuals in the community. While deinstitutionalization is welcome and broadly supported, it had some unintended consequences that still exist today. For instance, people with developmental disabilities and their families and caregivers often feel left on their own while trying to obtain health, mental health, community and developmental services. With regard to the education system, they have also struggled to ensure that it is welcoming for children and young adults with developmental disabilities. In general, developmental disability remains too closely associated with poor health, poverty, marginalization, social isolation, inadequate housing and homelessness.<sup>3</sup>

### **Developmental disabilities**

Many different terms have been used as labels to describe developmental disabilities. The familiar terms include mental retardation, learning disability, developmental disability, or intellectually disability. Often these terms are used interchangeably, but there are also subtle differences between the definitions of each term. The selection of a particular term can be influenced by where one lives, the policies and regulations of a particular locale, as well as the discipline or background of the speaker.

The definition of developmental disabilities adopted by the National Coalition for Dual Diagnosis is as follows:

Children, youth and adults who have significantly greater difficulty than most people with intellectual and adaptive functioning and have had such difficulties from a very early age (or the developmental period prior to age 18). 'Adaptive functioning' means carrying out everyday activities such as communicating and

---

<sup>1</sup> World Health Organization (2001). Report 2001 -- Mental Health: New Understanding, New Hope. Geneva, Switzerland.

<sup>2</sup> 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.

<sup>3</sup> Radford, J. & Park, D. (2003). Chapter 1: Historical overview of developmental disabilities in Ontario. *Developmental disabilities in Ontario. I.* Brown and M Percy (Eds). Toronto, Ontario: Ontario Association on Developmental Disabilities.

interacting with others, managing money, doing household activities and attending to personal care.

This definition of developmental disability also includes children, youth and adults with developmental disorders such as Fetal Alcohol Spectrum Disorders or Autism Spectrum Disorders.

## **Mental health and mental illness**

Mental health (or well being) is an ideal we all strive for. It is a balance of mental, emotional, physical and spiritual health. Caring relationships, a place to call home, a supportive community, and work and leisure all contribute to mental health. However, no one's life is perfect, so mental health is also about learning the coping skills to deal with life's ups and downs the best we can.

Mental illness is a serious disturbance in thoughts, feelings and perceptions that is severe enough to affect day-to-day functioning. Examples of mental illness are depression, bipolar disorder and schizophrenia – although there are many more diagnoses.

## **Dual diagnosis**

Dual diagnosis is most often understood as encompassing people with a substance abuse disorder and a mental illness. People with developmental disabilities and mental health needs have variously been referred to as having a dual diagnosis, a concurrent disorder<sup>4</sup> or a co-morbidity.<sup>5</sup> Sometimes for clarity sake, the longer definition, *children, youth and adults living with lifelong developmental disabilities and mental health needs* is preferred. In terms of this paper, we are calling this dual diagnosis.

People with dual diagnosis have more severe symptoms, are more likely to have co-occurring medical conditions and have fewer resources (access to education, social and economic supports). They are also more likely to require long-term hospitalization.<sup>6</sup>

'Challenging behaviours' is a term that has been used to describe aggression, self-injury, and destructive, disruptive or non-compliant behaviours that can be an expression of symptoms related to physical or mental health needs.<sup>7</sup> Unfortunately such responses may also expose individuals to threats, excessive force, and caregiver anger. As result they may then experience even further isolation as families, significant others, caregivers and communities struggle to respond to these complex dynamics.

People with dual diagnosis also suffer the "double jeopardy" of stigma, further marginalizing and isolating them.

One result is that their mental health needs are often missed - for a number of reasons:

---

<sup>4</sup> Dual diagnosis and concurrent disorders can mean either developmental disability and mental health need or mental health needs and substance mis-use – depending on the jurisdiction in question.

<sup>5</sup> Co-morbidity is best understood as a physical illness and a mental health need.

<sup>6</sup> *ibid*

<sup>7</sup> 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.

- Challenging behaviours, as a result of an emerging mental health need, may be misinterpreted as another manifestation of the developmental disability.
- A diagnosis of developmental disability can over-take a person's entire identity where new symptoms are seen only as an extension of the disability rather than evidence of a physical or mental illness.
- Similarly, recent changes in behaviour that may signal a mental health need can be dismissed or ignored.
- In many cases, people with developmental disabilities are already prescribed psychiatric medications to address the challenging behaviours. Over-medication may mask a real mental health need that requires assessment, diagnosis and perhaps a different regimen of medication.
- People with developmental disabilities can develop competencies and skills in an effort to appear normal and in order to avoid rejection or bullying. Caregivers may be lulled into thinking nothing is wrong – when these skills, once adaptive, now serve to conceal real pain.
- Some people with developmental disabilities have exceptional talents or abilities that divert caregivers from seeing that they have physical and mental health needs.
- People with developmental disabilities often have communication difficulties and are unable to tell caregivers what, exactly, is wrong.

As a result there is a tendency toward inaccurate mental health diagnosis, inappropriate treatments (such as too many or too much medication), complicating and confounding side effects due to over-medication, frequent contact with police and hospital emergency rooms, and failure in community programs.

This is a group that has complex needs yet most service systems are not well equipped to deal with complexity. Education, health, community and developmental service professionals are not trained in responding to people with developmental disabilities and mental health needs. They are also not used to working in inter-professional care teams where the many professionals needed to respond to complexity are available in one location. Individual services can also do a poor job of communicating with one another, leaving families scrambling to coordinate services themselves. Government policies that affect people with developmental disabilities, in general, are scattered across multiple levels and ministries with no harmonization. Often there is no specific policy for this group.

### **Inadequate access to the positive determinants of health**

Access to quality health and mental care – when ill – is important in determining Canadians' health status. But even more important is access to what are called the positive determinants of health, defined as education, housing, nutrition, economic security, work, safe communities and social inclusion. People with dual diagnosis are substantially disadvantaged in their access to these valuable opportunities.

In Canada, research indicates that children with disabilities are five times more likely to be abused than the general population.<sup>8</sup> Of the children with developmental disabilities who have been abused, 35.9% continue to live with the perpetrator.<sup>9</sup> In addition, children

---

<sup>8</sup> The National Clearing House on Family Violence. Available at: [http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/html/nfntsdisabl\\_e.html](http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/html/nfntsdisabl_e.html)

with developmental disabilities are more likely to live in families at the lower end of the income scale while 77% of adults with a developmental disability live in poverty.<sup>10</sup>

UK research found that only 30% of adults with a developmental disability had a friend who was not part of the family or paid to care for them.<sup>11</sup>

The key issue for children with developmental disabilities is that they can be missed in the school system and identified only later. As a result they do not receive help with their education in the early years when it is so important for them.<sup>12</sup> Only 33% of Canadians support inclusive education for children with developmental disabilities.<sup>13</sup>

Adults with developmental disabilities prefer real jobs as opposed to sheltered workshops. However supported employment models have resulted in few people acquiring and maintaining jobs in the community because of the high level of supports required.<sup>14</sup> Sixty percent of people with developmental disabilities are out of the labour force.<sup>15</sup>

Estimates of developmentally disabled persons in Canada's criminal justice system range from 2 – 36%.<sup>16</sup> The range in percentage is broad, as there are wide variations in how offenders are identified as developmentally disabled.

In addition, estimates of people with dual diagnosis among the homeless or inadequately housed range from 10 – 15%<sup>17</sup> up to 40 – 50%<sup>18</sup>.

All these factors combine to create extremes of health inequity.

---

<sup>9</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

<sup>10</sup> *ibid*

<sup>11</sup> *ibid*

<sup>12</sup> *ibid*

<sup>13</sup> Canadian Association for Community Living (2007). Inclusion of Canadians with intellectual disabilities.

<sup>14</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre. *ibid*

<sup>15</sup> Canadian Association for Community Living (2007). Inclusion of Canadians with intellectual disabilities.

<sup>16</sup> Hasssan, S. & Gordon, R. (2003). Developmental disability, crime and criminal justice: A literature review.

The Criminology research Centre, Simon Fraser University. Available at: <http://72.14.205.104/search?q=cache:tPJvLy0ZoXgJ:www.sfu.ca/crc/fulltext/hassangordon.pdf+Number+of+offenders+who+have+a+development+disability&hl=en&ct=clnk&cd=3&gl=ca>

<sup>17</sup> Personal communication (2008). Donna Lougheed (2008).

<sup>18</sup> (May 2008) Working in Vancouver

## Health inequity

People with developmental disabilities or a dual diagnosis have much poorer health than the general population.

They:

- Age earlier and have a higher mortality rate;
- Lead sedentary lifestyles and have more cardiovascular disorders;
- Have high rates of obesity;
- Have lower vaccination rates;
- Have mental health problems at a 3 – 6 times higher rate than the general population;
- Have more teeth extracted rather than treated than the general population;
- Can have 3 -4 times the rate of *helicobacter pylori* infection – an infection associated with the subsequent development of peptic ulcers and gastric cancer;<sup>19</sup> and
- Are less likely to receive preventative screening in primary care settings (for example, mammograms, PAP smears, PSA testing, flu shots, or fecal-occult testing).<sup>20</sup>

Further, both the physical and mental illnesses that they experience are often undiagnosed and thus untreated because of the unique issues they face in receiving appropriate care. In part this is due to difficulties in communication by clients, adjustments required to the standard diagnostic process to make accurate diagnoses for this group and lack of skill and training among care professionals.

Due to histories of institutionalization, they:

- 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, reality can be in fact 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; and
- Families and caregivers often have to relocate to find services, yet our public health system guarantees portability.

---

<sup>19</sup> Quелlette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied research in Intellectual Disabilities*. Vol 18, p. 113 – 121.

<sup>20</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

In their turn, many families wanting to help are left without support. They are doing the best they can but are breaking under 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; and
- 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.

### **Families, friends and caregivers**

Those that care for children, youth and adults with developmental disabilities and dual diagnosis also have needs that are often ignored. They suffer significant financial burdens and may have to move communities in order to find services for their loved one. They can feel isolated and marginalized from family and community and may have their own physical and mental health problems related to the stresses of constant care. They may feel excluded and blamed by professional providers and find that their views and opinions are ignored. Dealing with multiple levels of government, the complications of obtaining funding, and accessing uncoordinated services can leave families, significant others and caregivers feeling frustrated and drained. Respite care and access to their own support services is inconsistently available.

### **A National Coalition on Dual Diagnosis**

A group of individuals, families, organizations and associations from a variety of sectors formed in 2008 to develop a consensus of opinion and advocate for change.

The sponsors of the group are:

**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, promotes 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:** 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 multidisciplinary 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](http://www.camh.net/Care_Treatment/Program_Descriptions/Mental_Health_Programs/Dual_Diagnosis/index.html)

## The Coalition's recommendations

This national coalition developed a set of recommendations of what must happen if the lives of people with a dual diagnosis are to improve.

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 instills 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, 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.
- c. **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%<sup>21</sup> up to 40 – 50%.<sup>22</sup>

### **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

---

<sup>21</sup> Personal communication (July, 2008). Donna Lougheed, Psychiatrist, Faculty of Medicine, University of Ottawa.

<sup>22</sup> Personal communication (May, 2008). Developmental pediatrician (Chris Lock, MD) working in Vancouver regarding her own research.

Disabilities section of the Canadian Psychiatric Association, and the Dual Diagnosis Program, Centre for Addiction and Mental Health.

**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.

**Conclusion**

People with dual diagnosis are Canadian citizens deserving of health equity. Because of their disabilities and the double jeopardy of stigma, they have unequal access to the opportunities that most citizens enjoy. Despite these challenges, they have strengths and abilities. The national coalition believes that the time has come for them to be acknowledged in a National Mental Health Strategy.