



## Dual Diagnosis Frequently Asked Questions

Prepared by  
National Coalition on Dual Diagnosis



Developmental Disabilities Section of the  
Canadian Psychiatric Association



NADD Ontario

## **1. What is meant by 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.

## **2. What is a developmental disability?**

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.

**Definition:** 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 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 Disorder or autism with significant impairment in adaptive living skills.

There are well over twenty commonly recognized causes of developmental disability. A few include Down Syndrome, Fragile X Syndrome, Prader Willi Syndrome. Their proportionate number is increasing as genetic determinations of particular syndromes become possible. However, approximately half of all persons with intellectual disabilities cannot yet be diagnosed with a genetically determined test and remain 'undifferentiated.' Over the past 30-40 years we have also seen the recognition of Pervasive Developmental Disorders (Autism Spectrum Disorders, Asperger Syndrome, Heller's Dementia and Rett Syndrome), Fetal Alcohol Spectrum Disorders, survivors of extreme prematurity with developmental disabilities and the continuing adverse effects of famine and war on children's development throughout the world. All of these developmental disabilities are associated with a range of other conditions and co-morbidities for which individuals having them are at higher risk than average because of the nature of their conditions.

The common causes of death of persons with developmental disabilities are different than for the population at large with respiratory, cardiac difficulties and infections most common. There are also studies determining that people with developmental disabilities experience the detrimental effects of aging much earlier in life than in the population at large.

## **3. Why are people with developmental disabilities susceptible to mental health problems?**

People with developmental disabilities can be vulnerable on many levels. Seventy-seven percent of adults with a developmental disability live in poverty.<sup>1</sup> In Canada, research indicates that children

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<sup>1</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

with disabilities are five times more likely to be abused than the general population.<sup>2</sup> Abuse is not only physical or sexual assault, but also being yelled or screamed at, insulted, having disability checks stolen and signatures forged, neglecting basic needs, and threats.<sup>3</sup> Sixty percent of people with intellectual disabilities are unemployed.<sup>4</sup> Developmental disability is also associated with an increased prevalence of co-morbid disabilities and disorders, including hearing, vision, motor impairments, seizures, and other medical and communication difficulties that can lead to poor health. Many are isolated and have few friends.

#### **4. What is the “double jeopardy” of stigma?**

The “double jeopardy” effect of stigma 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,”<sup>5</sup> meaning that mental health problems are ignored and untreated because the symptoms are judged to be “just” part of the developmental disability.

#### **5. What do the families friends and caregivers of people with dual diagnosis need?**

Families, friends and caregivers are the primary provider of care for individuals with a dual diagnosis, often long into their senior years. 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. They also require 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. In addition, families require a choice of meaningful day supports/programs for their loved ones that enhance their lives.

#### **6. Why do the education, health, community and developmental service systems have difficulty meeting the needs of people with dual diagnosis and their families?**

In general, most systems tend to respond well to people who have single or short-term problem. People with dual diagnosis have complex and multiple problems that require systems to work together in order to be effective. However, these systems have separate ministries, separate policies and procedures. Until very recently, professionals and para-professionals were not trained to work in care teams. As a result, few multi-disciplinary care teams are presently practicing at all, let alone in dual diagnosis. Individual providers or systems working in isolation have difficulty meeting the needs of people with complicated problems.

#### **7. Why form a National Coalition on Dual Diagnosis?**

In May 2008, a national coalition of individuals, families and representatives from organizations was formed. The coalition felt it was time people with dual diagnosis and their families and caregivers spoke with one voice in Canada. The needs of people with dual diagnosis are complicated. The coalition’s aim is to communicate these issues in clear and compelling language.

<sup>2</sup> The National Clearing House on Family Violence. Available at: [http://www.phac-aspc.gc.ca/nfv-cnivf/familyviolence/html/nfntsdisabl\\_e.html](http://www.phac-aspc.gc.ca/nfv-cnivf/familyviolence/html/nfntsdisabl_e.html)

<sup>3</sup> Horner-Johnson, W. & Drum, C. (2006). Prevalence of maltreatment of people with intellectual disabilities: A review of recently published research. *Mental Retardation and Developmental Disabilities Research Reviews*. Vol 12, pg 57 – 69.

<sup>4</sup> Canadian Association for Community Living (2007). Inclusion of Canadians with intellectual disabilities.

<sup>5</sup> Reiss, S. & Szyszko, J. (1983). Diagnostic overshadowing and professional experience with mentally retarded persons. *American Journal of Mental Deficiency*. 87, p. 396 – 402.

Members of the coalition believe if Canadians are able to understand, they will ask governments to take a greater interest in caring for this vulnerable group.

## 8. Who are the sponsors of this National Coalition?

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, 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)

## 9. What can help people with dual diagnosis?

People with a dual diagnosis – across their life span - ***do not presently have timely or adequate access*** 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.

## **10. What does the National Coalition recommend?**

- Develop enabling government policies at all levels.
- Ensure professional and para-professional preparedness through training and education.
- Develop programs to help families, friends, and caregivers.
- Fund research to collect accurate data and develop best practices.

*People with a dual diagnosis 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.*

## **11. What can the Mental Health Commission of Canada do?**

The Mental Health Commission of Canada ([www.mentalhealthcommission.ca](http://www.mentalhealthcommission.ca)) has a concern for the mental health of *all* Canadians. It has pledged to develop a National Mental Health Strategy in the next several years. The National Coalition believes that it is important that this strategy include people with developmental disabilities and mental health needs. 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 highlights that equal access does not necessarily mean equal outcomes (equity). When people with dual diagnosis are misunderstood, can't communicate or are denied services, yet have "access" to health care and other services, there can be no equity of outcome.