



## Dual Diagnosis Factsheet

Prepared by  
National Coalition on Dual Diagnosis



Developmental Disabilities Section of the  
Canadian Psychiatric Association



NADD Ontario

# Dual Diagnosis

## The facts about...

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

### 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 intellectual 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 Disorders or Autism Spectrum Disorders.

#### For more information regarding definitions and terminology consult:

- The American Association of Intellectual and Developmental Disabilities  
[http://www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml)
- The Canadian Association for Community Living  
<http://www.cacl.ca/english/aboutus/definitions.html>
- Centres for Disease Control and Prevention  
<http://www.cdc.gov/ncbddd/dd/dd1.htm>
- Fletcher, R., Loschen, E., Stavrakaki, C., First, M. (2007) Intellectual Disabilities. In Diagnostic Manual – Intellectual Disability: A clinical guide for diagnosis of mental disorders in persons with Intellectual Disability. Editors: R.Fletcher, E. Loschen, C. Stavrakaki, M. First. NADD Press.

### Definitions of 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. Some types of mental illnesses are:

- Schizophrenia - seeing, smelling or hearing things that aren't there or holding firm beliefs that make no sense to anyone else but you – symptoms that are often called psychosis, noting that psychosis can be associated with other disorders such as depression or in relation to drug abuse,
- Depression - intense feelings of sadness and worthlessness – so bad that you have lost interest in life,
- Bi-polar disorder - cycles of feeling intensely happy and invincible followed by depression,
- Anxiety disorders - panic attacks, phobias, obsessions or post traumatic stress disorder,
- Eating disorders – anorexia (not eating), bulimia (eating too much and then vomiting), or binge eating disorder (eating too much and not purging – often leading to obesity), and
- Borderline personality disorder - severe difficulty with relationships, placing yourself in danger, making decisions that turn out to be very bad for you – most often as a result of a history of child abuse, abandonment or neglect. <sup>1</sup>

### **Recovery:**

“Recovery defines consumers, not as passive objects of treatment, but as active participants – along with their families and caregivers - in creating and maintaining their own mental health. Recovery focuses on wellness rather than illness. Recovery is not a cure. There is no timeline. It is living life to the fullest despite challenges.

Consumers say that recovery is much more than just dealing with the symptoms of mental illness. People have other life experiences that have affected their mental health. Recovery acknowledges and validates all these experiences and opens the door to a broader base of coping mechanisms than simply diagnosis, medication or therapy.”<sup>2</sup>

### **Prevalence Rates for Developmental Disabilities**

Important note: Most figures are based on people with developmental disabilities who receive services. It is estimated that prevalence rates are, in fact, much higher as many do not access formal services.

- Estimated prevalence rate of developmental disabilities in the general population: **1 – 3%**.<sup>3</sup>
- Estimated number of children and adults in Canada with developmental disabilities: **up to 1 million**.<sup>4</sup>

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<sup>1</sup> Training in Partnership Curriculum (2007). Developed by The Dual Diagnosis Implementation Committee of Toronto and George Brown College. Author: Barbara Everett, Ph. D.

<sup>2</sup> Working together towards recovery: Consumers, families, caregivers and providers. A publication of the Canadian Collaborative Mental Health Initiative. Available at: [Hhttp://www.ccmhi.ca/en/consumers.html](http://www.ccmhi.ca/en/consumers.html) p. 5 - 6 and p. 39.

<sup>3</sup> World Health Organization (2001). Report 2001 -- Mental Health: New Understanding, New Hope. Geneva, Switzerland.

<sup>4</sup> Canadian Association for Community Living (November, 2007). Inclusion of Canadians with Disabilities.

- Percentage of people with developmental disabilities who also have:

<b>Physical disability</b>	<b>30%</b>
<b>Hearing impairment</b>	<b>20%</b>
<b>Epilepsy</b>	<b>20%</b>
<b>Communication disorders</b>	<b>30%</b>
<b>High blood pressure</b>	<b>43.3%</b>

- A conservative estimate of the percentage of people with a developmental disability who also have a mental health problem: **38%**.<sup>5</sup>
- Overall number of people in Canada with a developmental disability and a mental illness: **380,000**.<sup>6</sup>
- The percentage of people diagnosed with autism that also have an intellectual disability: **50 – 70%**.<sup>7</sup>
- The estimated percentage of people with developmental disabilities due to a genetic condition: **50%**.<sup>8</sup>
- The remainder of developmental disability is attributed to environmental causes (for example, malnutrition, disadvantaged environment, accidents, poisoning, abuse, and childhood disease) or catastrophic health events such as prenatal infection or exposure to unspecified toxins and other prenatal concerns such as vascular malformations/stroke, or premature death.
- The percentage of extremely premature babies (below 800 grams) who develop lifelong developmental disabilities: 14%
- The leading cause of preventable birth defects in North America: **Drinking alcohol during pregnancy**.<sup>9</sup>
- Number of babies born in Canada annually with Fetal Alcohol Syndrome: **365 – one per day**.<sup>10</sup>

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<sup>5</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>6</sup> *ibid*

<sup>7</sup> Baird, G. Simonoff, E. Pickles, A. Chandler, S. Loucas, T. Meldrum, D. & Charman, T. (2006). Prevalence of disorders of the disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* 368: 210-215.

<sup>8</sup> Chudley A.E. (2004). Advances in the Genetics of Developmental Disabilities, in *Developmental Disabilities: Etiology, Assessment, Intervention, and Integration*, Williams, WL (ed.). Context Press, Reno Nevada.

<sup>9</sup> Whitfield, M.T. Gruneau, R.V. E. & Holsti, L. (1997). Extremely premature (below 880 g) schoolchildren: Multiple areas of disability. *Archives of Disease in Childhood*. Vol 77, p. 85-90.

<sup>10</sup> CCSA Literature Review: Evaluation strategies in Aboriginal Substance Abuse Programs: A discussion. (2004) Available at: [Hwww.ccsa.ca/H](http://www.ccsa.ca/H).

## Dual Diagnosis: Developmental Disabilities and Mental Health Problems

- The percentage of people in tertiary care psychiatric hospitals who have a developmental disability and a mental illness: **12.5% or 1 in 8**.<sup>11</sup>
- People who have both a developmental disability and a mental illness 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>12</sup>
- The percentage of people with developmental disabilities who have challenging behaviours: **10%**. Challenging behaviours are defined as aggression, self-injury, and destructive, disruptive or non-compliant behaviours.<sup>13</sup>
- Mental health disorders are more common among people with profound intellectual disabilities than the general population. Many have more than one mental health problem. The most common problems are mood disorders and challenging behaviours.<sup>14</sup> UK researchers found that there was an increased risk of psychopathology in children and adolescents with an intellectual disability.<sup>15</sup> Specifically, psychiatric disorders were found in **36%** of children and adolescents with intellectual disabilities but only 8% in those without a disability. Social disadvantage was associated with increased incidence levels of mental health problems.<sup>16</sup>
- Ontario data on prevalence rates of developmental disability in combination with a psychiatric disorder has encountered problems defining both “developmental disability” and “psychiatric disorder.” As a result, researchers tend to report a range (**15 – 60%**).<sup>17</sup>
- In the Netherlands, **25.8%** of total disease-specific health costs were accounted for by mental disorders: **10.6%** for psychiatric disorders, **9.0%** for intellectual/developmental disabilities, and **6.2%** for dementia.

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<sup>11</sup> Lunsky, Y. (2006). The clinical profile and service needs of adults with mental retardation and a psychiatric diagnosis. *Psychiatric Services*. Vol 7(1), p. 77 – 83.

<sup>12</sup> *ibid*

<sup>13</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.

<sup>14</sup> Cooper, SA. Smiley, E. Finlayson, J. Jackson, A. Allan, L. Williamson, A. Mantry, D. & Morrison, J. (2007). The prevalence, incidence and factors predictive of mental-ill health in adults with profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. Vol 20, p. 493 – 501.

<sup>15</sup> Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*. Vol 47. Part 1, p. 51 – 58.

<sup>16</sup> Emerson, E. & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*. Vol 198, p. 493 – 499.

<sup>17</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.

- Health care costs for intellectual disabilities/developmental disabilities rose **5.4%** from 1988 – 1994. <sup>18</sup>

## **Lack of Access to the Social Determinants of Health and its Impact**

### Abuse

- In Canada, research indicates that children with disabilities are **5 times** more likely to be abused than the general population. <sup>19</sup>
- Of the children with developmental disabilities who have been abused, **35.9%** continue to live with the perpetrator. <sup>20</sup>
- Abusers tend to be men (**89%**). Of those incidents of sexual assault on women with intellectual disabilities, **53%** are by male service recipients (also intellectually disabled), **20%** by staff and **8%** by family members.
- Research has shown that there is a very low rate of prosecution for sexual abuse of persons with intellectual disabilities. People with developmental and/or intellectual disabilities who have been sexually assaulted show the same range of emotional symptoms after the assault as does the general population. <sup>21</sup>
- In studies of women with intellectual disabilities, those reporting sexual abuse range from **25 – 33%**.
- 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>22</sup>

### Poverty

- Children with developmental disabilities are more likely to live in families at the lower end of the income scale.

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<sup>18</sup> Polder, J. J. Meerding, W. J. Bonneux, L. & VanderMaas, P. J. (2002). Health care costs of intellectual disability in the Netherlands: A cost of illness perspective. Journal of Intellectual Disability Research. Vol 46 (2), pg. 168 – 178. Available at:

[Hhttp://www.ingentaconnect.com/content/bsc/jidr/2002/00000046/00000002/art00009H](http://www.ingentaconnect.com/content/bsc/jidr/2002/00000046/00000002/art00009H)

<sup>19</sup> The National Clearing House on Family Violence. Available at: [Hhttp://www.phac-aspc.gc.ca/nctv-cnivf/familyviolence/html/nfntsdisabl\\_e.html](http://www.phac-aspc.gc.ca/nctv-cnivf/familyviolence/html/nfntsdisabl_e.html)

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

<sup>21</sup> Pecham, N. G. (2007). The vulnerability and sexual abuse of people with learning disabilities. British Journal of Learning Disabilities. Vol 35, pg. 131 – 137. Note that the term for intellectual disability in the UK is learning disability.

<sup>22</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.

- **28.8%** of children with developmental disabilities live in households where the income is in the low or the lowest quintile as opposed to **17%** of children without disabilities.<sup>23</sup>
- **77%** of adults with a developmental disability live in poverty.<sup>24</sup>

### Isolation

- 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>25</sup>
  - **33%** find it harder than average to make friends
  - **25%** find it hard to keep friends
  - **14%** have no friends
  - **43%** can't talk to a friend when they are upset or worried.<sup>26</sup>

### Education

- In Ontario, **15%** of children receive special education funding. The key issue for children with developmental disabilities is that they are missed in the school system and identified only later so they don't get help with their education in the early years when it is so important for them.<sup>27</sup>
- Only **33%** of Canadians support inclusive education for children with developmental disabilities.<sup>28</sup>

### Employment

- Adults with developmental disabilities prefer real jobs as opposed to sheltered workshops but supported employment models have not resulted in people getting and keeping jobs in the community in very large numbers because of the high level of supports required.<sup>29</sup>
- **60%** of people with intellectual disabilities are out of the labour force.<sup>30</sup>

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<sup>23</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

<sup>24</sup> ibid

<sup>25</sup> ibid

<sup>26</sup> ibid

<sup>27</sup> ibid

<sup>28</sup> Canadian Association for Community Living (2007). Inclusion of Canadians with intellectual disabilities.

<sup>29</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre. ibid

<sup>30</sup> Canadian Association for Community Living (2007). Inclusion of Canadians with intellectual disabilities.

## Health Inequities

- Adults with developmental disabilities
- Age earlier and have a higher mortality rate than the general population
- 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  
Are less likely to receive preventative screening.<sup>31</sup>

## Criminal Justice System Involvement

- Estimated percentages of developmentally disabled persons in Canada's criminal justice system range from **2 – 36%**. The range in percentage is broad as there are wide variations in how offenders are identified as developmentally disabled.<sup>32</sup>
- The percentage of men involved in the Canadian criminal justice system (pre-trial detention) with intellectual disabilities (ID) – also called developmental disability: **19% with a probable diagnosis of ID and 29% with borderline ID.**<sup>33</sup>

## Homelessness

- Estimates of people with dual diagnosis among the homeless or inadequately housed range from 10 – 15%<sup>34</sup> up to 40 – 50%.<sup>35</sup>

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<sup>31</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

<sup>32</sup> Hasssan, S. & Gordon, R. (2003). Developmental disability, crime and criminal justice: A literature review. The Criminology Research Centre, Simon Fraser University. Available at: [Hhttp://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=caH](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=caH)

<sup>33</sup> Crocker, A. Cote, G. Toupin, G. & St-Onge, B (2007). Rate and characteristics of men with intellectual disabilities in pre-trial detention. *Journal of Intellectual and Developmental Disabilities*. Vol 32(2). P. 143 – 152. For the abstract, see: [Hhttp://dx.doi.org/10.1080/13668250701314053H](http://dx.doi.org/10.1080/13668250701314053H)

<sup>34</sup> Donna Lougheed (2008), personal communication.

<sup>35</sup> Personal communication (May, 2008). Developmental pediatrician (Chris Loock, MD) working in Vancouver regarding her own research.

## Families

- US data shows that **80 – 85% of children and adults with developmental disabilities will live with their families** until their parents' health declines or they die.
- **77%** of adults with developmental disabilities are presently living with parents who are 60 or over.<sup>36</sup>
- In southeastern Ontario, **94%** of children with developmental disabilities who receive services live with their parents; **45%** of those 18 – 44 years of age and **12%** for those over 45 live with their parents.<sup>37</sup>
- US figures show that **60%** of children and adults with developmental disabilities live with their families, **13%** in their own home and **15%** with a spouse.<sup>38</sup>
- In England and Wales, ordinary community placements account for no more than **10%** of people with developmental disabilities who live outside the families with the remainder in some form of institutionalized or group setting.<sup>39</sup>
- In Australia, **7.8%** live in formal residential settings with the vast majority of people with developmental disabilities living with their families or caregivers.<sup>40</sup>
- Families are isolated. UK data reports that **less than one in three family caregivers** of children with a developmental disability and a mental health problem turn to other family members or friends for help or advice.<sup>41</sup>
- There is an increasing trend in the proportion of individuals in the US with intellectual disabilities and developmental disabilities living with family members. In 1992, **6.3%** of Medicaid recipients with developmental disabilities were living at home. In 1999, **22%** were living at home. In 2006, **38.8%** were living in a home with family members (most often parents).<sup>42</sup>
- Caregivers (mostly mothers) spend **50 – 60 hours per week** on caring for their disabled child/adult.<sup>43</sup>

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<sup>36</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

<sup>37</sup> ibid

<sup>38</sup> Bradock, D. Emerson, E. Felce, D. Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the US, Canada, England and Wales and Australia. Mental Retardation and Developmental Disabilities Research Reviews. Vol 7, p. 115 – 121.

<sup>39</sup> ibid

<sup>40</sup> ibid

<sup>41</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

<sup>42</sup> Lakin, K. Charlie, Prouty, R., & Coucouvanis, K. (2007). HCBS recipients are increasingly likely to live with parents or other relatives. Intellectual and Developmental Disabilities. Vol 45, pg. 359-361.

<sup>43</sup> Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre.

- The prevalence of challenging behaviours among children and adults with developmental disabilities leads to increased stress in family caregivers. It also places the child or adult at greater risk of abuse, neglect and deprivation.<sup>44</sup>

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<sup>44</sup> Lowe, K. Allen, D. Jones, E. Brophy, S. Moore, K. & James, W. (2007). Challenging behaviours: prevalence and topographies. Journal of Intellectual Disability Research, Vol 51(8), pg. 625-636.