

# APPENDIX 1 DEVELOPMENTAL DISABILITIES

<b>Depression, Early Psychosis, Anxiety, and Substance Use Disorders in People with Developmental Disabilities</b>	<b>6.2</b>
<b>Basic principles of Mental Health in Developmental Disability</b>	<b>6.2</b>
<b>Treatment Principles for Mental Health in Developmental Disability</b>	<b>6.2</b>
<b>Frequent Psychiatric Disorders in People with Developmental Disabilities</b>	<b>6.3</b>
<b>Syndromes Associated with a High Incidence of Mental Health Disorders</b>	<b>6.5</b>
<b>Fetal Alcohol Spectrum Disorder</b>	<b>6.5</b>
<b>Autism Spectrum Disorder (ASD)/ Pervasive Developmental Disorder</b>	<b>6.6</b>
<b>Down Syndrome</b>	<b>6.6</b>
<b>Fragile X Syndrome</b>	<b>6.6</b>
<b>Dedicated Health and Mental Health Services Available</b>	<b>6.6</b>
<b>References and Resources</b>	<b>6.7</b>

### DEPRESSION, EARLY PSYCHOSIS, ANXIETY AND SUBSTANCE USE DISORDERS IN PEOPLE WITH DEVELOPMENTAL DISABILITIES

- In BC, long-stay institutions for people with DD have been closed since 1996.
- A *developmental disability* means sub-average intellectual functioning equivalent to an IQ of 70 or below, as well as impaired adaptive skills, and occurrence prior to age 18. (definition of *mental retardation* in DSM-IV or DSM-IV-TR)
- Those who meet the full criteria for developmental disability are probably about 1% of the population.
- The diagnosis of *mental retardation* in the DSM-IV or DSM-IV-TR classification system is coded on AXIS II.
- Services to people with DD are provided by Community Living Services MCFD

### BASIC PRINCIPLES OF MENTAL HEALTH IN DEVELOPMENTAL DISABILITY

- People with DD can develop the full range of psychiatric disorders.
- IQ does not predict prognosis or response to treatment.
- The presentation of psychiatric illness in people with DD may range from typical to atypical.
- People with DD experience a very significant rate (30 – 40%) of mental health disorders based on estimated prevalence rates, yet many are typically underdiagnosed, misdiagnosed, and underserved
- The most frequent reason for a request for psychiatric assessment is aggression or self injury for people with DD, but aggression or self-injury are often the outward symptoms of common mental health disorders, or a physical cause or environmental change.
- The most commonly occurring disorders, similar to the general population, include major depressive disorder, bipolar disorder and anxiety disorders.
- Higher rates of physical, emotional, and sexual abuse may also be responsible for a higher rate of mental illness.
- Medical conditions may present with psychiatric symptoms more frequently than in the general population.
  - Undiagnosed or improperly treated physical problems can affect a person’s behaviour and may lead to over-diagnosing of ‘behaviour’ problems, misdiagnosis of personality disorder and/or psychotic disorders resulting in over-prescribing of psychotropic medications, especially antipsychotic medications.
- Ensure that informed and valid consent is obtained for health care for people with DD
  - Be aware of British Columbia’s Adult Guardianship Legislation when working with people with DD ([www.trustee.bc.ca](http://www.trustee.bc.ca) for information).

### TREATMENT PRINCIPLES FOR MENTAL HEALTH IN DEVELOPMENTAL DISABILITY

- People with DD have the same requirement for treatment as others in a health authority but care and sensitivity must be taken to accommodate to their disability.
- Consider and seek out reports of family, third party caregivers, or associated support staff and make adaptations to accommodate to the individual’s communication needs.
- The language of the interview must be significantly altered.
  - Use plain language, short sentences, speak slowly and avoid leading questions.
- Allow for adequate time for physical examinations, mental health and addiction assessments.

**FREQUENT PSYCHIATRIC DISORDERS IN PEOPLE WITH DEVELOPMENTAL DISABILITIES**

*Depression*

- Common presentations include:
  - tearfulness, sad, irritable or angry affect
  - social withdrawal or increased dependency, regression in self-care skills or loss of learned skills
  - aggression or self-injurious behaviour
  - decreased energy or psychomotor retardation
  - appetite change or sleep disturbance
  - hypochondriasis or tantrums
  - reduced speech or mutism.
- Reporting of suicidal ideation, self-depreciation, and guilt may be difficult for many.
  - Individuals with DD may never meet full DSM-IV or DSM-IV-TR criteria.
- Although thought to be serious by the individual, suicidal behaviour may not always be lethal (e.g., self-strangling) or risk taking behaviour may occur (e.g., riding bike with eyes closed).
- Symptoms of hallucinations or delusions may occur more frequently with depression.

*Anxiety Disorders*

- Frequent in the DD population, but difficult to diagnose as identification of anxiety can be difficult for someone with DD.
- Significant anxiety may be reflected as a somatic illness, e.g., a stomach ache. In addition, severe anxiety can lead to behavioural problems.
- **Obsessive-compulsive disorder** is also identified frequently. Some individuals are able to articulate the anxiety associated with performing a compulsion, and others are not. There is a consensus that these conditions should be treated as they typically would even if the person appears to not be bothered by performing a compulsion.
- **Posttraumatic Stress Disorder (PTSD)** It is likely that individuals who have DD are at greater than average risk for experiencing repeated traumatization (Sobsey, et al., 1992). People with DD live, to varying degrees, in a state of dependency on others.
- The symptoms of PTSD may be quite different from those seen among the general population.
  - articulating the event may be difficult.
  - flashbacks and memories may be more vague or distorted.
  - increased anxiety and hyperarousal may present as a ‘behavioural problem’.
  - brief psychotic episodes may occur (Martorana, 1985).

*Psychotic Disorders*

- Because of verbal difficulties it is not thought possible to reliably diagnose psychosis in those with an IQ of less than 50.
- The rate of actual psychotic disorders may be similar to that in the general population, though this is still controversial as some studies suggest an increased prevalence.
- Onset of schizophrenia before adolescence is rare but tends to be somewhat earlier in people with DD than in the general population (Meadows et al, 1991).
- Imaginary friends, self-talk, dramatic fantasy play are usually not signs of psychosis.
  - Many fantasies *may* appear to be a delusional system, but when questioned carefully, the individual can indicate awareness that the subject of discussion is not real.
- People with DD may experience a higher rate of psychotic symptoms when under severe stress.
- As with other psychiatric disorders, aggression may also be a presenting problem.

*Overuse and Misuse of Anti-Psychotic Medications*

- Due to the frequent presence of aggression and self-injury, there has been a historical trend for overuse and misuse of antipsychotic medications for people with developmental disabilities.
- The use of anti-psychotics in this population is associated with greater risk of developing movement disorders (especially tardive dyskinesia and tardive akathisia) and cognitive impairment.
- Anti-psychotics are often prescribed for ‘behaviour’ without understanding what is behind the behaviour.
- Withdrawing someone from an antipsychotic medication after they have been on for many years must be done very slowly (5% – 10 % every 2 months) in order to minimize potentially very serious withdrawal effects (agitation, insomnia, confusion or aggression).
- If anti-psychotics must be used, start low and go slow.

*Substance Use Disorders*

- Incidence of substance use disorders appear to be low compared to the general population. It is likely to be underestimated and under diagnosed.
- Caffeine and nicotine-related disorders are the most frequently found disorders in this population. Alcohol or illicit drugs tend to be consumed in lower amounts as compared to the general population. Stavrakaki (2002)
- Enquire about *all* substance use (including cigarettes, caffeine, and over-the-counter medicine)
- Treatment tips:
  - make materials easy to read/comprehend
  - avoid abstract written and spoken material
  - keep sessions short (15 – 30 minutes)
  - supplement group with individual treatment
  - use modeling, rehearsal and feedback to teach skills

- enhance family/other support
- monitor impact of drug/alcohol use on concurrent medications
- use more concrete and short term goals.
- encourage a support person to attend sessions with the client to provide reinforcement of the concepts after discharge from treatment.
- treatment interventions that support reduction in stress and drugs craving, such as yoga and acupuncture, over cognitive based therapies common in the substance use field may be helpful with people with developmental disabilities (Sturme et al., 2003)

### SYNDROMES ASSOCIATED WITH A HIGH INCIDENCE OF MENTAL HEALTH DISORDERS

#### Fetal Alcohol Spectrum Disorder

- FASD refers to the range of birth defects caused by prenatal exposure to alcohol, including Fetal Alcohol Syndrome (FAS), Partial FAS and Alcohol Related Neurodevelopmental Disorder (ARND).
- It is estimated that 1 – 3 of every 1,000 live births in North America are affected by FAS, and rates of Partial FAS and ARND are likely to be much higher.
- It is the leading cause of preventable mental retardation.
- Recommend abstinence. There is no known safe level of alcohol consumption while pregnant.
  - Binge drinking is thought to be more harmful than consistent lower levels of drinking, since it raises the blood alcohol content to a higher level.
- *Primary disability:* The permanent neurodevelopmental deficits of Fetal Alcohol Spectrum Disorders ('brain damage') growth impairment and other birth defects.
  - facial changes including epicanthal eye folds
  - poorly formed concha
  - small teeth with faulty enamel
  - cardiac atrial or ventricular septal defects
  - aberrant palmar crease and limitation in joint movement
  - microcephaly
  - kidney, liver, hearing and sight may also be affected
- *Secondary disabilities:* (many of which can be mediated by proper interventions and support) include:
  - a very high rate of mental health/addiction problems and disorders (90%) such as suicide and suicide attempts, depression, anxiety, attention-deficit hyperactivity disorder; disrupted school experience;
  - trouble with the law (60%)
  - confinement in inpatient units for mental illness/substance use disorders or incarceration for a crime (50%)
  - inappropriate sexual behaviour (50%)
  - alcohol or drug use problems (30%)
  - dependent living (80%)
  - problems with employment (80%), (Streissguth & Kanter, 1997).
- Lack of a proper diagnosis results in higher concurrent disorders and can also lead to misdiagnosis of mental health/addiction disorders or over-diagnosis of personality disorders.

- Mental retardation (IQ less than 70) may or may not be present but most tend to have a marked discrepancy between IQ and adaptive functioning, with adaptive functioning almost always being lower than the IQ and adaptive function often falling below 70.
- For women with an alcohol or other substance use problem, consider referral to the BC Women's Hospital program at Fir Square which provides care for substance using women and their children, and also operates an outpatient clinic.
- When someone is diagnosed with FASD, it is important to consider the needs of two patients (mother and child). The highest predictor of having a child with FASD is already having a child with FASD

### **Autism Spectrum Disorder (ASD)/ Pervasive Developmental Disorder**

- Most have associated anxiety including panic attacks, compulsions and perseverative rituals that may result in challenging behaviours.
- Some have a severe form that includes relentless hyperactivity and severe sleep disturbance. In addition, there is a significant association with bipolar disorder in this population.

### **Down Syndrome**

- High rate of depression and anxiety disorders, with obsessive compulsive disorders frequently occurring.
- Individuals with Down Syndrome are also more prone to develop Alzheimer-like dementia at an earlier age, associated with accelerated aging problems.

### **Fragile X Syndrome**

- Most common inherited genetic disorder. In its full form it affects only males, but lesser forms of the condition are found in female family members as well.
- Associated with hyperactivity and some autistic features.
- Usually results in moderate to mild DD, and is also associated with (ADHD), hyperarousal, anxiety and aggression related to mood lability.

## **DEDICATED HEALTH AND MENTAL HEALTH SERVICES AVAILABLE**

### **Health Services for Community Living (HSCL) and Mental Health Support Teams (MHST)**

- Operated and managed by the Health Authorities.
- HSCL provides consultation in the areas of home nursing, physiotherapy and occupational therapy as well as nutrition and dental care.
- MHST provide assessment, treatment and consultation (to Family Physicians) for those individuals with DD and mental health needs who need special attention through Mental Health and Addiction Services.
- MCFD continues to provide some health services: specifically tertiary inpatient services (Willow Clinic) and professional behavioural support contractors for high need individuals throughout BC.
- Health Authorities provide the services of a Medical Consultant in Developmental Disability to Family Physicians. *(Find contact information under Resources at end of document)*
- See 4.10 for a listing of mental health support teams

## REFERENCES AND RESOURCES

The information in this appendix is excerpted from a much larger document: *Mental Health Services for People with Developmental Disability: Planning Guidelines for Health Authorities in BC* 2004. Ministry of Health Services, MHAS. The following references are specifically cited in this appendix:

- Martorana, G.R. (1985). Schizophreniform disorder in a mentally retarded adolescent boy following sexual victimization. *American Journal of Psychiatry*, 142, 784 – 786.
- Meadows, G., Turner, T., Campbell, L., Lewis, S.W., Reveley, M.A. & Murray, R.M. (1991). Assessing schizophrenia in adults with mental retardation. A comparative study. *Br J Psychiatry*;158: 103 – 5.
- Reiss, S. (1994). *Handbook of challenging behaviour*. Worthington, Ohio: International Diagnostic Systems.
- Ruedrich, S.L., Rossvanes, C.F., Dunn, J.E., & Delano, M.K. (2003). Cigarette Smoking, and the Use of Tobacco Products by Persons with Developmental Disabilities. *Mental Health Aspects of Developmental Disabilities*, 6, 99 – 106.
- Sobsey D, Sharmaine G, Wells D, Pyper D, Reimer-Heck B. (1992). *Disability, sexuality, and abuse: An annotated bibliography*. Baltimore: Paul H Brookes.
- Streissguth, A. & Kanter, J. (Eds.) (1997). *The Challenge of Fetal Alcohol Syndrome: overcoming secondary disabilities*. Seattle Washington: University of Washington Press.
- Sturmey, P. Reyer, H., Lee, R., & Robek, A. (2003). *Substance-related disorders in persons with mental retardation*. Kingston, New York: NADD Press.

*Resources*

The Advocate for Service Quality in British Columbia-assists adults with developmental disabilities and their families in obtaining high quality service from MCFD, from other ministries and service agencies Office: 1-604-775-1238 [www.mcf.gov.bc.ca/getting\\_help/advocate\\_service\\_quality.htm](http://www.mcf.gov.bc.ca/getting_help/advocate_service_quality.htm)

Bradley, E.A., Burke, L., Drummond, C., Korossy, M., Lunsky, Y. L., & Morris, S. (2002). *Guidelines for managing the client with intellectual disability in the emergency room*. Toronto: Centre for Addiction and Mental Health, University of Toronto, Surrey Place Centre. 1-800-661-1111 [www.camh.net/](http://www.camh.net/)

The Provincial Medical Consultant in Developmental Disability for BC: Dr. Brian Plain, Saanich Health Unit, #303-3995 Quadra St Victoria BC V8X 1J8 Telephone 1-250-744-5174; Fax 1-250-479-5836; [brian.plain@caphealth.org](mailto:brian.plain@caphealth.org)

*FASD Resources*

The FASD Fact Sheet includes information and where to find more help: [www.heretohelp.bc.ca/publications/factsheets/fetalalcohol.shtml](http://www.heretohelp.bc.ca/publications/factsheets/fetalalcohol.shtml)

The Fir Square program at BC Women’s Hospital: call (604) 875-2424, local 2160 on weekdays.

The FAS/E Support Network provides support for families with an affected child: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*Fetal Alcohol Spectrum Disorder: A Strategic Plan for British Columbia*: available at [www.healthservices.gov.bc.ca/mhd/fasd.html](http://www.healthservices.gov.bc.ca/mhd/fasd.html)