

PLANNING GUIDELINES FOR ...



Mental Health & Addiction Services for Children, Youth & Adults with Developmental Disability

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Qualifying Statement

This document highlights the approach and principal recommendations for planning mental health and addiction services for children, youth and adults with developmental disabilities. The Information and guidelines provided are based on:

- a thorough review of published research evidence, including comprehensive reviews
- examination of existing national and international services
- direct consultation with experts concerning service delivery models and planning guidelines

Readers should also note that the planning guidelines are not a standard of care and do not stipulate a single correct approach for delivering services or managing all clinical situations. Decisions regarding specific service development and clinical approach to the care for individuals with developmental disability remain the responsibility of service managers and attending professionals.

This document is available for download on the Ministry of Health web site, at <http://www.healthservices.gov.bc.ca/mhd/publications.html>.

Vision

Children, youth and adults in British Columbia with a developmental disability and mental health conditions should experience the highest quality of life possible, regardless of illness or disability. Impairments due to treatable conditions should be minimized through early intervention and timely, equitable access to appropriate mental health and addiction services. These services should be integrated, continuous, client-centred, and evidence-based. They should be provided in a manner that is appropriate and collaborative, and which respects the rights and dignity of the individual.

Executive Summary

These guidelines are intended to support the planning and development of mental health and addiction services for children, youth, and adults with developmental disabilities (DD) and co-occurring mental health disorders in British Columbia.

There is wide acknowledgment that people with a developmental disability are susceptible to the full range of psychiatric illnesses. The most commonly occurring disorders—similar to those in the general population—include major depressive disorder, bipolar disorder, anxiety disorders, and schizophrenia.

When compared to the general population, individuals with developmental disability have a higher rate of mental health disorders: 39 percent in children and 30 percent in adults (Emerson, 2003; Hudson C., Chan J., 2002; Smiley, 2005). Despite this, many are typically under-diagnosed, misdiagnosed, and underserved. This document describes a client-centred system of care that supports positive long-term mental health outcomes for these individuals.

Developmental Disability, Adaptive Functioning, and Eligibility for Services

The term *developmental disability* is one of many terms used to indicate delayed cognitive and impaired adaptive function, but developmental disability is not a diagnostic medical term with a consistent definition. In this document, the term *developmental disability* will be used in a broad sense, i.e. *developmental disability* will be assumed to include diagnoses of mental retardation (MR) as well as *other* developmental disorders, some of which are not linked to a specific range of IQ, but all developmental disorders share adaptive function deficits.

IQ alone is not sufficient to describe the global intellectual delay, and tests of adaptive function must be used as part of the diagnostic criteria. Adaptive functioning is a broad term and includes all skills involved in daily living, ranging from basic eating and dressing to accessing public transportation independently. The tests of adaptive function require a formal interview with someone who knows the individual well.

In British Columbia, Part 1 of the *Community Living Authority Act* provides a definition of developmental disability. This definition includes significantly impaired intellectual functioning that manifests before the age of 18 years and concurrent impaired adaptive functioning. Consistent with this definition,

A Definition

Developmental disability as defined in the *Community Living Authority Act* means “Significantly impaired intellectual functioning that:

- manifests before the age of 18 years,
- exists concurrently with impaired adaptive functioning, and
- meets other prescribed criteria.”

CLBC confirms the presence of a developmental disability through assessments provided by registered psychologists.

Barriers and Difficulties

The quote below reflects national and international concerns about communication barriers and access to health care for this population:

“Given that appropriate health care leads to better quality of life for individuals, and that to be effective in obtaining this health care individuals must have the ability to express their health concerns and problems, persons with developmental disabilities are at a distinct disadvantage: they often do not have the communication skills that allow them to articulate their health needs, and health care professionals usually do not have the skills to obtain the necessary information to enable diagnoses. For most individuals with developmental disabilities, their health care needs are determined by proxy, by family members or caregivers who best know the individual and by health care professionals who are often unfamiliar with the individual. As a result, both access to and utilization of health services are limited and thus persons with developmental disabilities do not have optimal quality of life” (Ouellette-Kuntz et al 2005).

Community Living British Columbia (CLBC) adopted developmental disability eligibility criteria for its services. These criteria emphasize onset in childhood, significant intellectual or cognitive limitations, and inability to adapt to the demands of everyday life.

In B.C., programs, associations, and services for individuals and families with a developmental disability, including the British Columbia Association for Community Living and CLBC, use the term “developmental disability” to identify individuals with MR.

The Model of the Continuum of Services

The model continuum of services for children, youth and adults with developmental disabilities and their families includes a comprehensive array of services from early childhood through older adulthood. The diverse range of services needed includes prevention; early identification; assessment; diagnosis; intervention; specialized assessment; assistive technologies; education; developmental skill building; behaviour management; and social, vocational, housing and residential supports, as well as specialized mental health services.

Designing Services

The design of effective services for individuals with developmental disabilities and mental health problems is based on principles consistent with other health care services, including the following:

Access

Access to services is directly related to the ability of people to cope with difficulties and avoid prolonged suffering and loss of functional abilities. Access to mental health and addiction services must include a range of resources to ensure the most appropriate (least restrictive) services are used at all times.

Access is measured by the time it takes to get help when needed, and by whether or not individuals get what they need when and where they require it. For most service planners and advocates, access to appropriate care is seen as the primary obstacle to overcome in order to promote effective treatment for people with developmental disabilities.

Quality

Service needs are determined by accurate diagnosis and treatment planning, in combination with careful consideration of how particular services affect the quality of an individual’s life. Quality of service requires a commitment to ongoing staff education and training. Direct support staff must have a high level

of awareness of mental health and psychosocial issues impacting this client population.

Professionals involved must be willing and trained to serve all individuals regardless of the level of developmental disability and the extent of the psychiatric impairment. A program designed to serve individuals that easily “fall through the cracks” in the system cannot be selective when choosing a clientele. In addition, there must be consensus among professionals in the community that there is a need for a comprehensive service program.

Unlike traditional case management, the models using the service linkage approach for this client population often have affiliation agreements or protocols that are negotiated administratively between systems and major stakeholders rather than being based on individual service needs alone. This is the predominant approach used by program models found in North America and Europe to improve the mental health care of individuals with a developmental disability (Bouras, Holt, Murphy, et al. 2001).

Effectiveness

Effective mental health and addiction service provisions for this client population must be community based because that is where most informal resources for this population are found. *Developmental mental health* requires interdisciplinary assessment, understanding of developmental disability, and recognition of communication and behavioural issues. Behavioural changes can be a helpful barometer for a person with limited communication skills by signalling physical or psychological distress.

Appropriateness

Appropriateness of care must ensure excellence through careful attention to treatment approaches. It is possible, for example, to have access to care without receiving appropriate care. Thus, an individual may have quick access to an inpatient facility during a psychiatric crisis, but if the treating mental health team does not have an accurate diagnostic and treatment strategy, the services received will not be effective. Involving family members, primary caregivers, family physicians and specialized community mental health teams in care plans is essential.

Accountability

Service systems must be accountable to everyone involved. Quality service is individual-centred and outcomes are measured by an increase in quality of life rather than exclusively by a decrease in challenging behaviours or psychiatric symptoms. In addition, it is essential to recognize the central role of family and

In considering service design, bear in mind some of the key differences in service needs for this client population. These include:

- a greater involvement of multidisciplinary teams
- ongoing long-term support with flexible variations of intensity, recognizing the permanent nature of the developmental condition
- the need for integrated child, youth, and adult services.
- the need for protocols or affiliation agreements among major stakeholders

caregiver supports. Services must be user-friendly, with adequate attention to literacy support strategies and cultural sensitivity.

Cost-Effectiveness

Services must be cost-effective. When access, appropriateness, and effectiveness are considered, cost-effectiveness must be incorporated. A conflict can arise if attention to appropriateness of care and the need for access do not have equal importance compared with cost-effectiveness. When evaluating cost-effectiveness, data collection should include both qualitative as well as quantitative measures.

In order to ensure sustainable long-term services to people with developmental disabilities and mental health and addiction needs, service agreements between the various government bodies responsible for developmental services and those responsible for mental health/addiction services are essential. Clarity of the mandates of service providers will ensure consistent interpretation and application of policies and guidelines.

Anticipated Long-Term Outcomes

Over the last three decades, knowledge concerning the mental health and addiction needs of this population has increased significantly, leading to a better understanding of service needs and helping to identify key elements of an adequate and responsive evidenced-based health service system.

This document describes developmental disability, the occurrence of mental health conditions, and the services needed to address these conditions. It describes what works in other jurisdictions and in current best practice, with the aim of supporting service planning in BC. Key services are proposed for school age children, youth, and adults. Together, these services provide a continuum of mental health care across the lifespan for individuals with developmental disabilities.

Anticipated long-term positive outcomes include:

- improved mental health through early identification and remediation of disabling mental health conditions

- reduced secondary disabilities such as social isolation, self-injurious behaviour or other challenging behaviours resulting from untreated mental health and co-morbid¹ health conditions
- timely identification, assessment, diagnosis, treatment and ongoing appropriate care for their mental health conditions
- stronger, healthier families, better able to provide positive support for individuals with disabilities
- reduced stigma and discrimination owing to their developmental disability and mental health condition
- self-empowerment through improved choice, access, validation, and responsiveness of mental health services
- improved quality of life for individuals, their families, and caregivers

Positive system outcomes include:

- early effective intervention
- appropriate capacity of the continuum of services to respond to the mental health and addiction needs of individuals with developmental disability
- appropriate utilization of health care services
- appropriate accommodation within the system to address the unique needs of this client population through enhanced training and awareness

¹ See Appendix D, “Glossary of Definitions and Acronyms,” for a definition of this and other terms.

Introduction

These guidelines are intended to support the planning and development of mental health services within British Columbia for individuals from age six to adulthood with developmental disabilities and co-occurring mental health disorders.

The document describes developmental disability, the occurrence of mental health conditions, and the services needed to address these challenges. It describes what works in other jurisdictions and in current best practice, with the aim to support service planning in BC. Key services are proposed for school age children, youth, and adults. Together, these services provide a continuum of mental health care across the lifespan for individuals with developmental disabilities.

In B.C., programs, associations, and services for individuals and families with a developmental disability, including the British Columbia Association for Community Living and CLBC, use the term “developmental disability” to identify individuals with MR.

Over the last three decades, knowledge concerning the mental health and addiction needs of this client population has increased significantly, leading to a better understanding of service needs and helping to identify key elements of an adequate and responsive evidenced-based health service system.

There is wide acknowledgment that people with developmental disabilities are susceptible to the full range of psychiatric illness. The most commonly occurring disorders, similar to those in the general population, include major depressive disorder, bipolar disorder, anxiety disorders and schizophrenia. When compared to the general population, individuals with developmental disability have a higher rate of mental health disorders, yet are typically under-diagnosed, misdiagnosed, and underserved (Emerson, 2003; Hudson C, Chan J, 2002; Smiley, 2005).

The presentation of psychiatric illness in someone with a developmental disability is often first identified as a problem of aggression or self-injury, but the best approach to diagnosis is an integrated approach that combines understanding of the behaviour in the context of the mental health symptoms. The level of a person’s IQ does not predict prognosis or response to treatment for mental or physical disorders. Knowledge of the client’s level of adaptive function is essential in order to determine the degree of support that is needed for follow-up care. Care and sensitivity must be taken into account to accommodate the

CASE EXAMPLE 1

An example of team role in providing staff education and training to decrease client aggression

A 50-year-old man with moderate developmental disability living in a 24-hour staffed group home was referred because of the home's difficulty managing his frequent aggressive outbursts. Interventions initiated by the specialized developmental disability mental health team included minor medication dosage adjustments and staff in-service sessions and education regarding bipolar illness provided at the group home site. Behaviour management plans and accompanying documentation protocols were initiated. These interventions have been effective in decreasing the frequency and severity of this man's aggressiveness.

individual's disability. Health care providers will benefit from specific training about the physical and mental health needs of this client population.

Measuring key mental and physical health indicators for this client population is essential to achieving improved health outcomes. The mental health of persons with developmental disabilities should be addressed through timely identification, assessment, diagnosis, treatment, and ongoing appropriate care of their mental health conditions, thus reducing the downstream impact on services over the long-term. People with a developmental disability must be assessed and treated within a systems framework that includes family members, professional support staff, and significant support people.

Service delivery should focus largely on specialist multi-disciplinary teams that are trained in developmental disability and mental health. Their aim should be to maintain people in their normal community setting through timely assessment and treatment while supporting informal and professional caregivers and families, and linking efficiently with specialist services when required. Services should be provided for children, youth, and adults and be characterized by integration and continuity. Appropriate capacity of regional acute care psychiatric beds should be available to support community teams. These units, in turn, should be supported by step-down capacity² in the community to reduce acute care admissions, provide alternate levels of care when needed, provide emergency placement options, and provide specialized psychiatric respite care. Crisis prevention and stabilization services should be available at a regional level with arrangements for after-hours response.

² See Appendix D, "Glossary of Definitions and Acronyms," for a definition of this and other terms.

CHAPTER 1: Developmental Disabilities - Definitions and Descriptions

The term *developmental disability* is one of many expressions used to indicate delayed cognitive and impaired adaptive function³, but developmental disability is not a diagnostic medical term with a consistent definition. Developmental disability is not an accepted psychiatric term and developmental disabilities cannot be used in a DSM-IV-TR⁴ diagnosis. There are no diagnostic codes in DSM-IV-TR for developmental disability. The terms *developmental disability* (DD) or *intellectual disability* (ID) are used in different parts of Canada. The current preferred international term is *intellectual disability*, but we will use the term *developmental disability* throughout this document, as this is the language most commonly used in BC. Other terms such as *mental handicap*, *mental deficiency*, *developmentally challenged*, *developmental delay*, and *learning disability* are used in the literature and are generally similarly defined.

The Government of Canada mentions developmental disabilities in various documents and in various departments but there is usually no actual definition given. As an example, in a document from Health Canada on *Family Violence and People with Intellectual Disabilities*, it states that “The term *developmental disability* is sometimes used interchangeably with *intellectual disability*, but usually refers to a wider class of disabilities that begin in childhood and have lifelong effects.” (http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/pdfs/fvintellectu_e.pdf)

In the United States, legislation defines developmental disability broadly to include MR as well as *other types of developmental disabilities* such as high-

Note

In this document, the term *developmental disability* will be used in a broad sense, i.e. *developmental disability* will be assumed to include diagnoses of MR as well as other developmental disorders, some of which are not linked to a specific range of IQ, but all developmental disorders share adaptive function deficits.

³ Adaptive functioning or adaptive behaviour is the effectiveness or degree to which an individual meets the standards of personal independence and social responsibility expected for age and culture group—in the areas of self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (Leezak, M., 1988).

⁴ Diagnostic and Statistical Manual of Mental Disorders IV-TR (DSM-IV-TR), published by the American Psychiatric Association. Describes consensus diagnostic guidelines for psychiatric disorders in North America.

functioning Autistic disorder (without intellectual disability), Asperger's Syndrome, brain injury, epilepsy, cerebral palsy, and neurodevelopmental disorders such as Fetal Alcohol Spectrum Disorder, where IQ for the individual is above the limit for MR but there are marked adaptive functioning deficits. For an example of the broader developmental disability definition, see the State of Oregon's eligibility requirements⁵.

In BC, eligibility for Community Living Services is now legislated under the *Community Living Authority Act*, which came into effect July 1, 2005. Section 1 of this Act defines *developmental disability* to mean significantly impaired intellectual functioning that:

- manifests before the age of 18 years
- exists concurrently with impaired adaptive functioning, and
- meets other prescribed criteria

Developmental disability is an evolving term and has only appeared in use within the last decade. It has different meanings for different professionals and often a different meaning than the term *intellectual disability* which may, at times and in some jurisdictions, be used as an equivalent to MR.

The term *developmental disability* is seen as less pejorative and has fewer negative associations than using the term *mental retardation*. However, it is important to understand that MR, as defined in the *Diagnostic and Statistical Manual of Mental Disorders IV-TR* (DSM-IV-TR)⁶, published by the American Psychiatric Association and the revised definition produced by the American Association on Mental Retardation⁷, is a defined medical term. The currently accepted definition of MR (since 1973) is related to age, IQ, and level of adaptive function. MR is characterized by sub-average intellectual functioning equivalent to an IQ of 70 (+/- 3-5) or below obtained on an individually administered intelligence test; sub-average overall adaptive skills; and documentation that this condition began during the developmental period prior to age 18 years.

⁵ In Oregon, the upper age limit for making the decision about someone having a developmental disability is higher (age 22) than in BC (age 18). See <http://www.oregon.gov/DHS/dd/eligibility/home.shtml#infoneeded> for details.

⁶ APA, 1994/TR 2000

⁷ AAMR, 2003

Community Living British Columbia (CLBC) confirms the presence of a developmental disability through assessments, which are described on the CLBC website at the following address: <http://www.communitylivingbc.ca>.

Dual Diagnosis

The term *dual diagnosis* is used in some jurisdictions to refer to the co-occurrence of a developmental disability and a co-occurring psychiatric disorder, as opposed to the other use of *dual diagnosis* that signifies concurrent mental disorder and substance use disorder. In this document, use of *dual diagnosis* will signify *developmental disability* and a concurrent mental health disorder.

Diagnosis of Developmental Disability and MR

Developmental disability is a condition that requires significantly impaired intellectual functioning and impaired adaptive skills, along with documentation that this condition began during the developmental period prior to age 18. The diagnosis is the result of assessment and overall clinical judgment regarding these factors. There are many causes of developmental disability. Thus, the population is very heterogeneous.

Most people with MR also have some type of a developmental disability but not everyone with a developmental disability has MR. For example, autism is a developmental disorder that can occur in a person with borderline intellectual functioning or normal cognitive ability, or it can co-occur in the presence of MR. Asperger's Syndrome is, like Autism, one of the Pervasive Developmental Disorders, but by definition (according to DSM-IV-TR) MR is not present in Asperger's Disorder. Fetal Alcohol Spectrum Disorder (FASD) is another example of a developmental disorder that may or may not be accompanied by an IQ in the range of MR. The deficits in adaptive function in FASD are often moderate to severe.

Making a diagnosis of MR is at times controversial, as different tests can produce a range of results and differences in interpretation can vary among psychologists and other health practitioners qualified to make this diagnosis. To meet the requirements for a diagnosis of MR, a qualified trained psychologist must first assess the person on a recognized and appropriately selected intelligence test (e.g., *Wechsler Adult Intelligence Scale, Third Edition*; *Stanford-Binet Intelligence Scale*, etc). However, intelligence testing alone is not sufficient to diagnose MR. Many people do poorly on these tests for reasons other than delayed cognitive development. For example, a person may be psychotic at the time of testing; may speak a language other than English; may be poorly educated; or may perform poorly for other possible reasons. For this reason, IQ

alone is not sufficient to describe the global intellectual delay (tests of adaptive function are also used as part of the diagnostic criteria, described below).

The second major requirement is significantly sub-average adaptive functioning, and this must be formally assessed as well. *Adaptive functioning* is a broad term. This includes all skills involved in daily living, ranging from basic eating and dressing to accessing public transportation independently. While no existing test measures all broad categories of adaptive skills, it is necessary to use one of the published scales of adaptive behaviour. In some jurisdictions, a global estimate of adaptive functioning may be determined by a social worker, a psychologist, or an occupational therapist. In British Columbia, eligibility for CLBC services requires that a psychologist perform both the intellectual and adaptive assessments to arrive at the overall diagnosis.

Individuals must always be compared to their language and cultural group. To give a more comprehensive picture of overall functioning, these assessments of intellectual level and adaptive function may be supplemented by separate testing of language and communication skills, as well as tests of academic achievement.

Classification of Level of MR

Planners and clinicians have thought it essential to know generally how delayed a person is, compared to others of a similar chronological age level. The DSM-IV-TR divides levels of MR into four categories: *mild*, *moderate*, *severe*, and *profound*. These classifications are illustrated in the chart below. For further detailed information on this topic, see page 73.

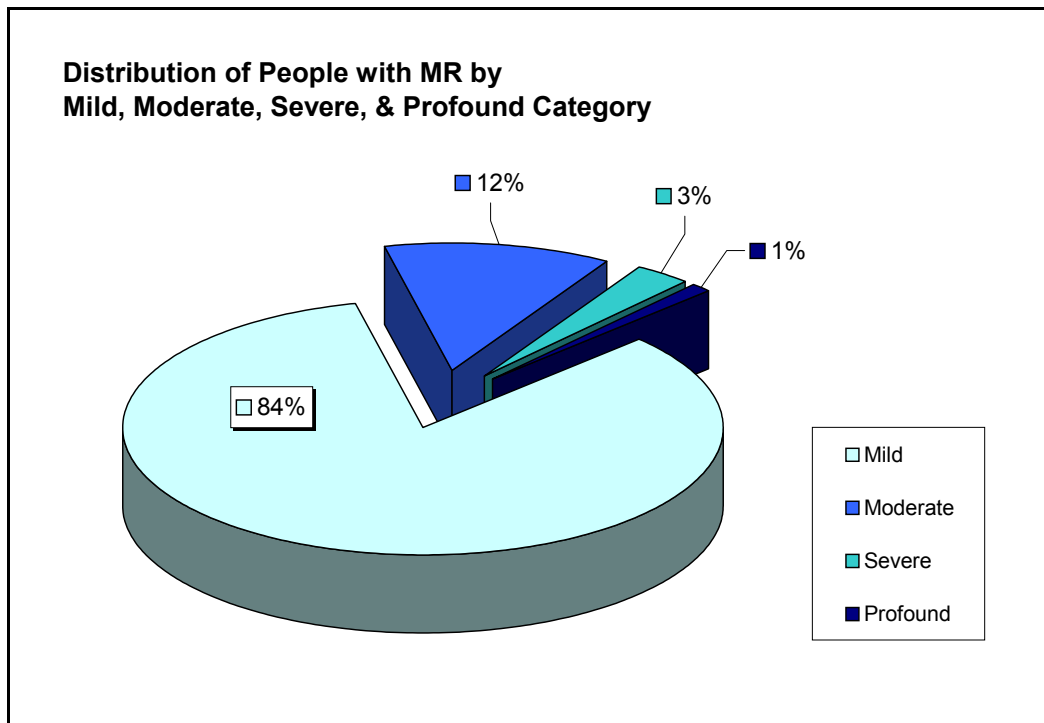


Figure 1: Distribution of people with MR by mild, moderate, severe, and profound categories of IQ scores

People functioning somewhat above these levels (i.e., *borderline intellectual functioning*), also constitute an important group who may be included in developmental disability services in some jurisdictions.

In B.C., the 2005 estimate for the general population is 4,254,522 individuals (<http://www.bcstats.gov.bc.ca/DATA/POP/pop/Project/p30notes.PDF>). This estimate includes 3,337,890 adults, 19 years and older, and 916,632 children and youth, under 19 years. It is estimated that one percent of this population (33,378 adults and 9166 children or 42,544 combined) will have MR (Mercer, 1973 a,b). Of this one percent, at least 39 percent of 9166 children and youth (3575) and 30 percent of 33,378 adults (10,013) require mental health services (Emerson, 2003; Hudson C., Chan J., 2002; Smiley, 2005). Thus, the total number of children, youth, and adults having MR and requiring specialized mental health and addiction services in BC is estimated to be 13,588. It is very difficult currently to estimate the number of individuals that might meet the broader definition of developmental disability.

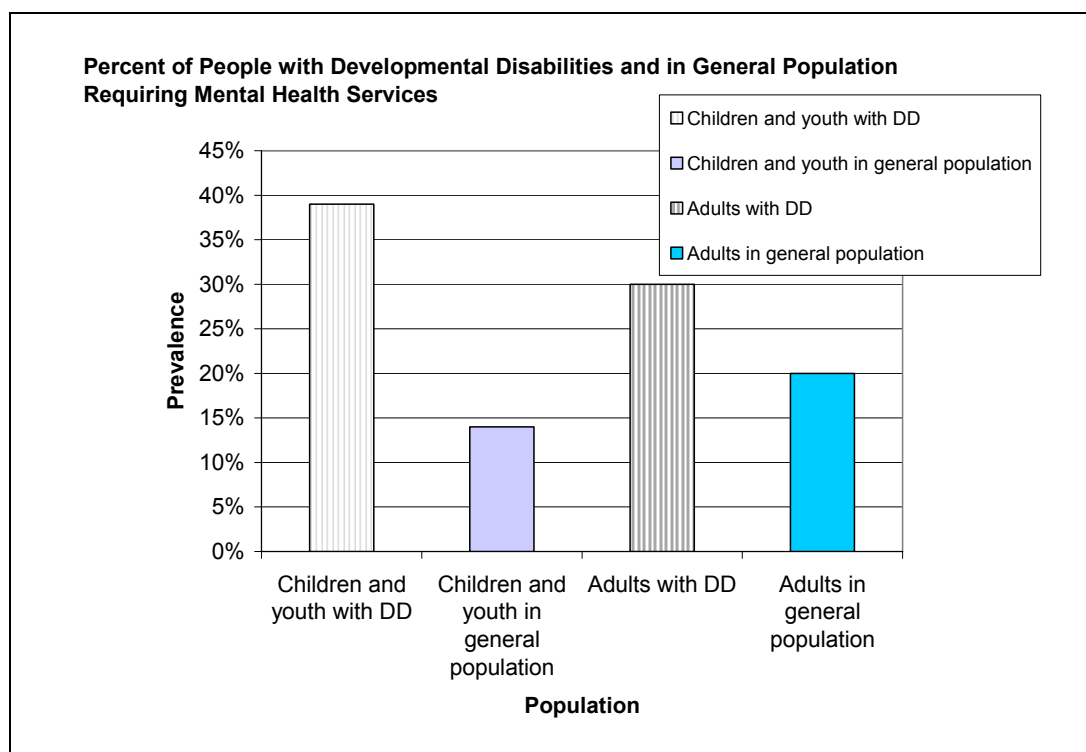


Figure 2: Percent of People with Developmental Disabilities and in General Population Requiring Mental Health Services⁸

Informed Consent

Much of the medical system and all of the legal system is based on the premise that people are mentally capable and able to understand what is told to them, and therefore are capable of making reasoned decisions for themselves. People with developmental disabilities have a range of abilities and disabilities, which may make it difficult for them to make valid decisions at times. People with developmental disabilities are vulnerable in systems that do not accommodate their needs or even recognize that there is a need to accommodate. Consent is a cornerstone of modern health care, but the route to obtaining **valid** consent from a person with a developmental disability can be complex and challenging. Informed and valid consent must be obtained prior to providing health care and support services for people with developmental disabilities, and substitute decision makers may be needed for many individuals, some or all of the time.

⁸ Emerson, 2003; Hudson C, Chan J, 2002; Smiley, 2005; Wadell et al., 2002.

An awareness of British Columbia's **Adult Guardianship Legislation** is essential for all health care providers (HCP) ⁹ when working with people with developmental disabilities, given the particular vulnerability of these individuals. Obtaining valid consent for treatment, or knowing when a *substitute decision maker*¹⁰ (SDM) or *temporary substitute decision maker* (TSDM) is needed requires familiarity with this legislation. The duties of a substitute decision maker are to give or refuse consent on the basis of the adult's known beliefs and values, or in the adult's best interests if his or her beliefs and values are not known. Prior to the decision, the substitute decision maker is to consult with the adult to the greatest extent possible, in order to try to determine what the adult's wishes would be. (See page 79 on for details of this and other important legislation.)

Requirements for Health Care Providers

Health care providers are required by law to:

1. Obtain a valid consent for health care. If the health care provider feels that the person with a developmental disability is not capable of giving valid consent, then the health care provider must determine if there is a substitute decision maker available (Committee of Person, representative, or the nearest qualified relative who is willing and able to give consent for the treatment). Contact the Public Guardian and Trustee for further information regarding this process.
2. Ensure that they gain and maintain specialized competence in developmental disabilities, and practice only in areas in which they have training, experience and qualifications.

⁹ *Health care providers include: nurses (RPN, RN, LPN); dentists, dental hygienists, dental assistants, denturists, and dental technicians; occupational therapists and physical therapists; social workers; physicians, naturopaths, and osteopaths; psychologists; acupuncturists; chiropractors and massage therapists; opticians, audiologists, and hearing aid dealers; podiatrists; and midwives.*

¹⁰ *Substitute decision makers include: a Committee of Person (court appointed); a representative named by the person; a temporary substitute decision maker (TSDM) named by a health care provider (usually near relative or next of kin). Ranking of TSDM includes spouse, common-law, or same-sex partner of the person; an adult child of the person; a parent of the person; a sibling of the person; or anyone related by birth or adoption.*

3. Seek and provide appropriate consultation, gathering detailed information from other sources, including previous assessments and family and support team members, prior to an evaluation and/or treatment of a person with a developmental disability.
4. Be aware of personal and societal biases and engage in non-discriminatory practices, offering, as a minimum, the accepted general standard of care to all persons under their care.

Causes of Developmental Disabilities

Causes of developmental disability are diverse and can include any condition that impairs development of the brain before birth, during birth, or in childhood and adolescence. Thus, the population is very heterogeneous. Major causes include:

- chromosomal abnormalities
- genetic or inherited factors such as Fragile X Syndrome
- problems of pregnancy and birth including prenatal exposure to alcohol and/or maternal malnutrition
- childhood injury or disease such as head injury or meningitis, and
- environmental factors such as poverty, neglect, or deprivation, resulting in malnutrition or inadequate medical care.

For about 50 percent of individuals, the cause of the disability cannot be identified. Of course, genetic factors and environmental influences can combine to determine an individual's intellectual level and adaptive behaviour. With advances in genetics, many individual errors on chromosomes are being detected, and we anticipate major advances in the understanding of causes of this type of developmental disability in the coming decades.

Problems Occurring During Pregnancy

Problems occurring during pregnancy that may cause a developmental disability can include difficulty physically maintaining the fetus, illness or injury in the mother, maternal malnutrition, and the effects of substance use on the developing fetus. Agents such as alcohol, street drugs, some prescribed medications, and other chemical substances influence the growth and development of the embryo or fetus when ingested by the mother. Examples of the effects of a teratogen are the birth defects seen in infants born to mothers who, during pregnancy, drank alcohol or took the prescribed medication thalidomide or an anti-seizure medication such as phenytoin.

Substance use during pregnancy is a growing and serious problem. Substances include alcohol, tobacco, and illegal and prescription drugs. Alcohol and other drugs can cause a wide range of birth defects as well as cognitive and other developmental disabilities (Streissguth & Kanter, 1997). Often, the effects on

learning and behaviour are not evident until school age. *Fetal Alcohol Spectrum Disorder* is a primary example of this. See page 109 for details.)

Unfortunately, the most common form of substance use today is poly-substance use, whereby the developing fetus is exposed to a combination of alcohol and illegal drugs, the combination of which significantly increases the risk of damage. For details, see page 107.

Recommended strategies for addressing substance use, depression, and related disorders during pregnancy and in the postpartum period are discussed in the B.C. Ministry of Health Mental Health & Addictions publication *Addressing Perinatal Depression: A Framework for BC's Health Authorities* (2006), available at: <http://www.healthservices.gov.bc.ca/mhd/publications.html>.

Additional Co-occurring Physical Disabilities and Health Conditions

People with developmental disabilities often have co-existing or concurrent health conditions. Research shows that this population tends to have more medical problems than the general population. Rates of morbidity are substantially higher than that of the general population, and a large proportion of medical conditions that go unrecognized are treatable and/or preventable.

For example, in the Netherlands, adults with developmental disabilities were found to be 2.5 times more likely to have diagnosed health problems than patients without developmental disabilities (van Shrojenstein Lantman-de Valk HM, Metsemakers JF, Haveman MJ, Crebolder HF, 2000). An Australian study showed that 95 percent of adults with developmental disability had health problems (Beange, McElduff & Baker, 1995). In addition, there is a higher rate of motor or sensory impairment among these individuals; many have visual, hearing, or physical impairments as well as obesity. Many genetic disorders include an array of impairments, which tend to be more frequent with severe and profound developmental disability and may have an associated higher mortality. See *Health Indicators and Health Disparities* on page 55 for more detailed information.

Some causes of developmental disability, such as prenatal rubella, are frequently associated with hearing impairment. Individuals with Down Syndrome, who represent the largest single group in the developmental disability population, have many associated physical conditions and illnesses. Seizure disorders occur in about 30 percent of people with developmental disabilities. Co-occurring medical, psychiatric, and behavioural problems are common. (See Epilepsy and physical and/or sensory impairment in the *Wales Health Evidence Bulletin* at <http://hebw.uwcm.ac.uk/learningdisabilities/chapter7.htm>.)

There can, however, be a mistaken diagnosis of developmental disability when a person has a significant sensory or physical impairment. In the past, it was not uncommon for a person who was deaf to be wrongly diagnosed as having a developmental disability. People with severe cerebral palsy are often incorrectly thought to be developmentally disabled because of associated speech impairment.

Psychiatric Disorders Co-occurring with Developmental Disability

This section provides a brief overview of the kinds of psychiatric disorders that can co-occur in people with developmental disabilities. For a comprehensive discussion and case examples, please see Chapter 5.

Definitions and Scope of Problem: The Challenge of Mental Illness among People with Developmental Disabilities

Over the last three decades, a major change has occurred in the way mental health clinicians understand people with developmental disabilities. There is now acknowledgment that people with developmental disabilities can develop the full range of psychiatric illnesses; that they have a higher rate of mental health disorders than the general population (Emerson, 2003; Hudson C, Chan J, 2002; Smiley, 2005); and that they also have a higher rate of physical health conditions. For more on this, see *Health Indicators and Health Disparities* on page 55.

Terminology

In the 1980s, people with developmental disabilities and co-occurring mental health problems were referred to as having a “dual diagnosis.” Since that time, this term, *dual diagnosis* has also come to mean “mental illness and substance abuse.” Some jurisdictions and some literature continue to use this term to refer to the developmental disability population with concurrent mental disorders.

This document concerns itself with all people who have developmental disability and another co-occurring mental health disorder. See Chapter 5 for a comprehensive discussion of developmental disabilities and co-occurring disorders.

In a meta-analysis of all studies at that time, Reiss found rates of mental health problems of 15 to 50 percent in adults with developmental disabilities (Reiss, 1994). He noted that low prevalence rates were generally found in surveys that relied on retrospective review of case files, while higher rates were found in surveys using professional interviewers and more elaborate scientific methods.

Reiss conducted a case-file retrospective review, finding a prevalence of 10 percent for mental health disorders in children with developmental delay among 5,637 public school case files in Illinois in the United States (Reiss, 1990). See Chapter 4 for additional research findings.

Frequency of Psychiatric Disorders

There is consensus in the literature that people with developmental disabilities experience a significant rate of mental health disorders based on estimated prevalence rates. At least 39 percent of children and youth, and at least 30 percent of adults with a developmental disability will require specialized mental health services. (Emerson, 2003; Hudson C, Chan J, 2002; Smiley, 2005). These prevalence rates are higher than estimated rates for mental disorders in the general population: children (14 percent) and adults (20 percent) (Wadell et al., 2002; Government of Canada, 2006).

<i>British Columbia¹¹</i>	<i>Adults (19 years & older)</i>	<i>Children & Youth (under 19 years)</i>
General Population	3,337,890	916,632
People with Mental Disorders	667,578 (20%)	128,328 (14%)
People with Developmental Disability	33,378	9,166
People with Developmental Disability & Mental Disorders	10,013 (30%)	3,575 (39%)

Table 1: Estimated Number & Percent of People with Developmental Disabilities and Mental Disorders vs. People in the General Population with Mental Disorders

¹¹ See <http://www.bcstats.gov.bc.ca/DATA/POP/pop/Project/p31notes.pdf>

CHAPTER 2: Planning Guidelines

The model continuum of services for children, youth and adults with developmental disabilities and their families includes a comprehensive array of services from early childhood through older adulthood. The diverse range of services needed includes prevention; early identification; assessment; diagnosis; intervention; specialized assessment; assistive technologies; education; developmental skill building; behaviour management; and social, vocational, housing and residential supports, as well as specialized mental health services.

These services are illustrated in the diagram below and discussed here in the context of two independent but concurrent service continuums. The *Mental Health Services Continuum* addresses the mental health needs of persons with developmental disability. A second service continuum which we are calling the *Continuum of Community Services* addresses housing, vocational supports, and other requirements of this population.

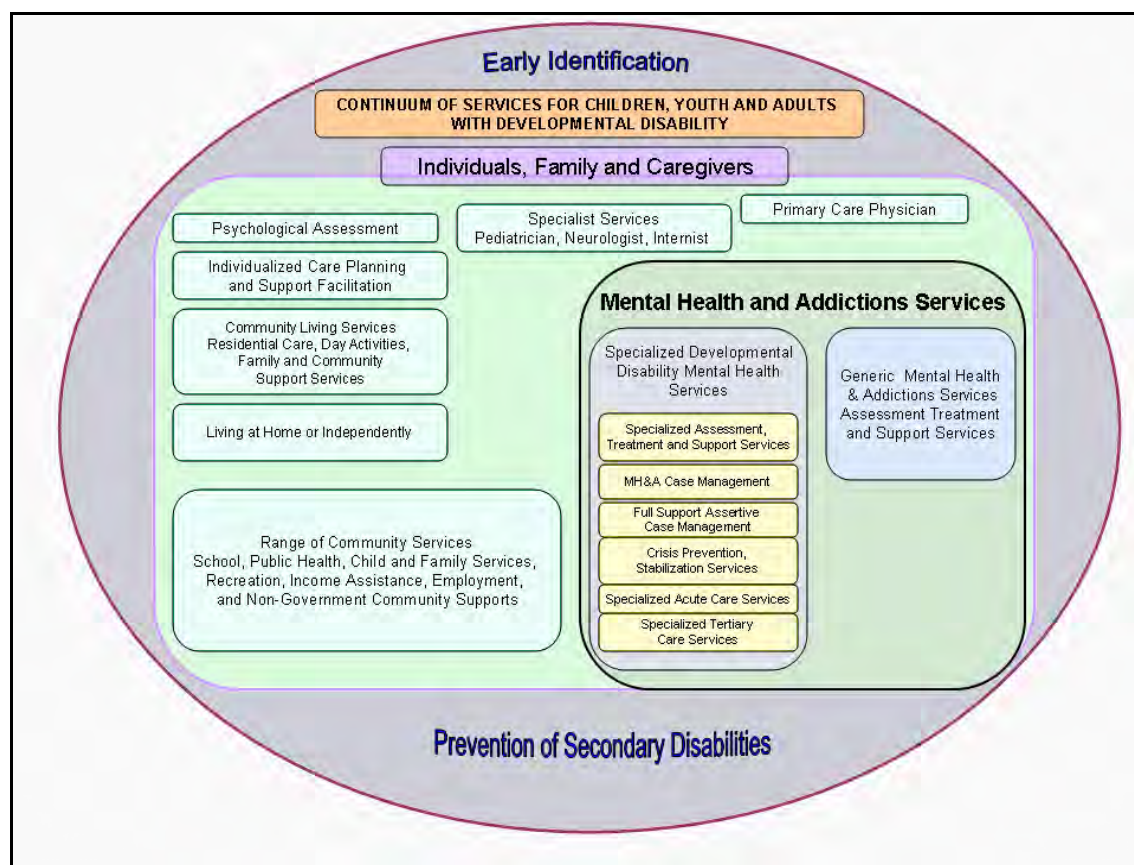


Figure 3: A schematic diagram of the continuum of services for children, youth, and adults with developmental disabilities.

The Mental Health Services Continuum

People with a developmental disability and a mental disorder require the same comprehensive continuum of care provided to other client populations served by mental health and addiction services¹². Some special accommodations are required in order for these services to be functionally equivalent. For example, a greater degree of specialized multi-disciplinary staffing trained in developmental disability and mental health and addiction, is required to address the unique clinical needs of this client population. Also, an integrated child, youth, and adult service continuum is essential for this client population in order to respond to cyclical periods of illness and ongoing

¹² See page 41 for a discussion of the Continuum of Community Services for children, youth and adults with developmental disability.

challenges of care. The goal of these services is to maintain people with a developmental disability and a mental disorder within their community setting through timely assessment and treatment, supporting informal and professional caregivers, providing input to the various community living services, and linking efficiently with specialist services when required. Adequate capacity of geographically distributed regional acute care beds is essential to support community teams by providing specialist acute assessment and treatment services. These units in turn rely on specialized community short-stay treatment beds and appropriate crisis intervention services.

Primary, Secondary, and Tertiary Mental Health Care

Consensus exists that a major barrier to effective care is imposed by the lack of clarity around defining care responsibility between mental health and addiction services and developmental disability services. Historically, the psychosocial supports and housing needs of this client population have received the majority of attention, with not enough attention paid to the mental and health care needs. Mental health and addiction services for individuals with developmental disabilities and concurrent mental disorders are needed at the primary, secondary and tertiary level.

Primary Mental Health Care

Persons with developmental disabilities typically access primary mental health care through their family practitioners. Primary care physicians need easy access to current health care information specific to developmental disability, quick reference guides to community services, and a list of specialty services. In addition to referral, the primary physician provides medical assessment and mental health screening. For children and youth, paediatricians are the primary psychiatric care providers.

Given the significant overlay of medical and mental health conditions, shared care and collaborative care approaches are reported to be effective in augmenting specialist psychiatric care for this client population.

Secondary Mental Health Care

This more specialized level of care includes specialized community assessment, emergency response, and local inpatient treatment services. Typically, this service includes assessment, treatment, consultation, and follow-up and is provided through a mental health team trained in the area of developmental disability. Staffing includes psychiatrists, psychologists, psychiatric nurses, social workers, occupational therapists, and behavioural communications specialists. Parents, family members, teachers and caregivers are essential team participants with regard to providing key information for diagnosis, discussing treatment decisions, and supporting the follow-up.

Interventions using a biopsychosocial framework include medications, psychosocial interventions, positive behavioural support, and environmental supports. Crisis intervention services focus on helping caregivers and families identify causes and remedies. They appropriately take into account earlier events, possible functions of the behaviour and communication, and generally attempt to effectively address the environmental, social, and biological factors involved. Interventions can reduce placements in intensively staffed residential care facilities and acute care hospitalizations. Follow up must continue as long as it is needed. Models successful in delivering secondary care demonstrate strong collaborative relationships with community, include interdisciplinary teams, and have timely access to the necessary continuum of mental health resources.

Tertiary Mental Health Services

Tertiary services are highly specialized. People who need such services have severe and disabling mental health conditions and need a 24-hour intensive and specialized service, for weeks or sometimes months. Specialized inpatient psychiatry units for people with developmental disability have characteristics similar to those for the general population of psychiatric patients. These include higher staffing ratios, occupational therapy, group therapies, specialized pharmacotherapy, psycho-education, enhanced structure, and rapid access to specialized medical and diagnostic services.

Collaborative discharge planning that begins at the time of admission or even pre-admission is essential to avoid unnecessarily increased length of stay.

Key Components in the Continuum of Mental Health Services and Service Models

Mental health assessment, treatment and ongoing support services for individuals with developmental disabilities are needed across a continuum of primary, secondary and tertiary care services including:

- Primary Care Physician Services
- Specialized Assessment, Treatment and Support Services
- Mobile Crisis Prevention and Intervention Services
- Specialized Community Crisis Stabilization Residential Services
- Specialized Acute Care Services
- Specialized Tertiary Care Services

Primary Care Physician Services

Description

Primary care physicians are often the first resource families turn to, to gain access to assessment, treatment, and support services of mental and physical disorders within

this client population. Many family physicians have less than adequate training in treating clients with developmental disability and mental disorder, given the complex clinical and behavioural issues in serving this client population (Burge, 2002). Clients with low functional abilities often have difficulty remembering or following through with treatment and some clients can be very disruptive in physician treatment settings, requiring support from accompanying family and care providers.

Family physicians may need to incorporate special accommodations to better serve this client population, such as: examining clients within their home environment, using special techniques to improve client communication, or conducting a physical examination over a series of appointments for those clients unable to tolerate a lengthy physical examination in one appointment. The family doctor will find that a well-informed caregiver or family member will be able to provide valuable information and guidance in dealing with complex behaviours and communication difficulties. As well, family physicians will often require support from specialists to ensure safe and effective treatment. Good communication among all treating physicians will enhance treatment outcomes.

An increasingly successful approach that attempts to address the problems of access and coordination/continuity of care is the concept of shared mental health care. In this approach, mental health specialists and family physicians work together as part of a well-coordinated mental health care delivery system that spans both mental and physical care.

Shared care promotes collaboration between providers from the different services or disciplines who share responsibility for the care of an individual. It creates opportunities to jointly discuss clinical matters in order to better manage the complex mental and physical health problems of this client population. It also provides opportunities for joint education to improve the skill and comfort level of the family physician in treating this client population.

Models

Models of shared care need to be adapted to local resource availability. There are many ways in which care can be shared, such as:

- Onsite consultation to family practice physicians or clinics by a specialist psychiatrist and/or specialized mental health clinician on a rotating basis to provide clinical consultation and education.
- The development of family practice specialists within a multidisciplinary specialized developmental disability mental health team and/or a full support case management team.
- Protocols for rapid access to consultation services by a specialist psychiatrist and/or specialized mental health clinician for family physicians.

BC's New Initiative for Improving Health Care

A good example of an innovative program for physicians following patients with complex needs is a recent addition to funding for family physicians in BC. The Ministry of Health and BC Medical Association General Practice Special Committee introduced in 2006 an initiative to increase payment to General Practitioners for care of patients with complex medical needs. This will include people of any age with a developmental disability, including Autism Spectrum Disorders and Fetal Alcohol Spectrum Disorder. The initiative recognizes the complexity and time that is required for physicians to provide medical care for complex patients in the community and provides funding for family physicians to attend interdisciplinary/community case conferences, thus enhancing communication, which will reflect directly on ongoing care.

- Holding joint clinic or educational rounds.

Guidelines for developing shared care are available on the national shared care website: <http://www.shared-care.ca>.

Specialized Assessment, Treatment and Support Services

Description

Specialized assessment, treatment, and ongoing support services for clients with developmental disability and mental disorder are an essential service component within the continuum of care. Services are provided by specialized teams consisting of multi-disciplinary mental health staff such as psychiatrists, nurses, psychologists, social workers, behavioural therapists, speech and language therapists, and occupational therapists, and may have access to other specialists such as music or art therapists. These teams provide detailed assessments of individuals and their environments, treatment and intervention programs, training and support of family carers and service staff, hands-on support to service staff at times of crisis and when introducing new client management programs, and counselling and support to family carers and service staff under stress. Services may be intermittent or time-limited for some, and others may require extended follow-up especially if complicated medication changes are occurring or there is a chronic and persistent mental disorder. Most of the clients receive ongoing community living support services. For some clients ongoing mental health case management or full support case management services are required.

Models

Specialized Developmental Disability Mental Health Team

The developmental disability literature consistently supports the need for specialist community-based developmental disability mental health teams (referred to as Teams). These teams focus exclusively on clients with developmental disabilities and mental health disorders who frequently have very challenging behaviours and other complex needs. The services of the team include detailed comprehensive assessments, treatment, intervention programs, time-limited or extended follow-up services to a full range of clients, including severely affected individuals living in the community and clients receiving care in hospital. Consultation and outreach treatment services are also provided to clients and staff in day programs and other community living services, as well as intensive clinical treatment services delivered through home and day program visits.

The advantages of these specialist teams has been reviewed by Emerson (2001), who noted that the teams were effective in providing support to clients in community settings, resulting in reduced symptoms and challenging behaviours, increased staff capacity to manage and support individuals, reduced number of admissions and re-

admissions to hospital and specialized units, and enhanced quality of life and adaptive functioning skills; moreover, these teams were found to be cost-effective.

➔ **Case Management Services**

Some clients with developmental disabilities and mental disorder have severe and complex symptoms and functional impairments requiring services beyond the time-limited services provided by the specialist teams. These clients require ongoing mental health case management services provided as an adjunct service by the specialist team or mainstream mental health centres with input from the specialist team. The case management services include ongoing comprehensive assessment, treatment, and intervention services; symptom management; relapse prevention such as trigger identification and the development of relapse prevention action plans; coaching and support of community living support workers; crisis intervention; and family counselling and support.

The literature confirms that high-quality case management services have been known to reduce inappropriate acute care hospitalizations and increase community tenure and housing stability. Case management services are typically implemented at costs significantly less than those of putting individuals in intensively staffed mental health community residential care facilities.

➔ **Full Support Assertive Community Treatment**

A small number of individuals with developmental disability and mental disorders have complex challenging behaviours, such as continuous physical aggression, inappropriate sexual behaviour, or setting fires, and require 24-hour full-support assertive community treatment services.

Full Support Model of Assertive Community Treatment with enhanced forensic, correctional, medical, and behavioural support is especially effective in serving individuals for whom previous, traditional treatment has been unsuccessful, including those with co-occurring substance abuse disorders and high use of inpatient acute care and correctional facilities.

Assertive Community Treatment (ACT) is an evidence-based outreach-oriented service model which utilizes a 24-hours-a day, 7-days-a-week, interdisciplinary, mobile team approach to treatment and ongoing care. It delivers comprehensive treatment, rehabilitation, and support services in community settings. The Full Support Assertive Community Treatment model combines the characteristics of ACT with various parts of the criminal justice and forensic system of care. It integrates corrections personnel (e.g. probation officers) and forensic staff into the case management team, with integrated addiction treatment and behavioural intervention services.

The literature confirms that Full Support ACT models have shown promising results with respect to addressing these complex challenging behaviours. Evidence shows

that, over time, most clients stabilize and do not require the intensity of a 24-hour Full Support ACT and are able to transition to less intensive services such as case management services provided through mainstream mental health and addiction services.

Mobile Crisis Prevention and Intervention Services

Description

Individuals with developmental disability and mental disorders experience mental health crises, such as acute disturbance of behaviour that requires immediate intervention. The goal of crisis intervention services is to stabilize the individual to the point where risk of harm to self or others is minimized; the person has returned to a level of functioning that does not require continued provision of an urgent/emergent level of care; and the individual can follow through with a course of treatment in a community-based setting.

The literature confirms the need for mobile crisis prevention and intervention services as key elements of the continuum of care, such as primary crisis response teams consisting of multidisciplinary staff, nursing and behavioural support workers with access to mainstream on-call psychiatry services. This team may be integrated with the specialist mental health teams described above in order to access the range of expertise required. The team is immediately accessible to caregivers and community agencies and provides urgent response. When not engaged in community response, such teams provide proactive training in the development of crisis response plans. In addition to specialized clinical skills in crisis management, they work as community resource experts, with strong collaborative links with all available services. They provide direct support to clients as well as training, modeling, and coaching to families and caregivers in dealing with complex clients. Working closely with the specialist team, the crisis team provides involvement with pre-identified clients. They establish supportive relationships with both caregivers and clients to produce an individual crisis behaviour plan to use when emergencies arise. They act to prevent placement breakdown by providing a flexible range of support hours as needed.

Models

The models of these primary crisis response teams vary widely and the design is determined by the relationship to other services such as the specialist teams, community residential care, and acute care services. Some models integrate the service with mobile Mental Health Community Response Teams (CRT) and in other areas they are attached to developmental disability services. The crisis response is closely coordinated and formally linked with other aspects of care. This integration provides the necessary range of functions to intervene in and prevent inappropriate responses to crisis situations. Without appropriate integrated crisis response services, the system of care remains in crisis along with the individual, and often results in an over-utilization of inappropriate resources such as acute care emergency rooms. The

role of the crisis prevention and intervention team includes urgent response as well as long-term crisis management and prevention. The team may also provide assistance to acute care services when an admission to hospital is unavoidable. Assistance in managing the client through admission as well as facilitating planning for discharge are valuable contributions of this service and can aid in achieving a timely discharge.

The urgent response capacity may be integrated into the system of community beds in order to provide a financially feasible 24-hour response (Beasley 2003). This crisis response component would only be used for after-hours situations where the individual requires immediate response that cannot wait for the primary response team's involvement.

A home treatment model provides increased resources that are brought in to prevent an impending admission.

In urban areas, a mobile response team may be a viable model if linked with multi-agency emergency service programs (Pfadt, 2005).

Specialized Community Crisis Stabilization Residential Services

Description

Specialized Community Crisis Stabilization Residential services provide community-based support for individuals with developmental disabilities and mental disorder in mental health crisis and perform a fourfold function: to divert individuals from unnecessary hospitalization or to shorten their hospital stay; to reduce community residential placement breakdown by providing emergency and planned respite; to stabilize the crisis without requiring inpatient care; and to develop, with the client, family and care providers, a support system that will sustain the client following discharge from the community crisis stabilization setting.

Models

One of the earliest and most successful models demonstrating how these residential crisis services can be integrated into a continuum of care is the START (Systemic, Therapeutic, Assessments, Respite, and Treatment) program operating in Massachusetts since 1989. The START program includes: Collaborative Contacts, which are crisis prevention planning meetings; consultation visits, treatment planning meetings, and follow-up meetings; After Hours Contacts, in which START provides 24-hour mobile crisis services; and Emergency Meetings, which are team meetings facilitated by START clinicians on a psychiatric inpatient unit or at the emergency respite facility following an admission. In addition, the START program provides planned and emergency respite care where people can live for short periods of time when they are in distress or in need of specialized crisis support and assistance. For further details see Appendix D of this document.

Specialized Acute Care Services

Description

Some clients with developmental disability and a mental disorder in mental health crisis require services beyond community crisis stabilization services as defined earlier in this report. The literature confirms the need for Specialized Acute Care Crisis and Stabilization Services for people with developmental disabilities and more intractable mental disorders as part of the continuum of services.

These specialized acute care services provide short-term assessment, treatment and support services through multi-disciplinary staffing, including: psychology, occupational therapy, specialized nursing, and psychiatry specialists, as well as access to medical specialists. The staff in these specialized units is highly skilled in managing behaviours across a wide range of clients. The services include extensive use of structured day programs with a focus on basic life skills and therapeutic activities. Behavioural and occupational therapy assessments are key in determining the specific day activities the individuals are best suited to.

Specialized Acute Care Services, as well as Community Crisis Stabilization Residential Services and Specialized Tertiary Care Services have developed a variety of environmental adaptations within these units to better serve this client population, such as (Morris, S., 2005):

- seclusion rooms with music, bean bag chair, pine wainscoting, and a wall mural
- padded seclusion rooms
- snoezelen room – multi-sensory interventions to provide stimulation and relaxation
- intensive observation units
- fenced private courtyard with garden atmosphere, maintained by the patients
- gender-separated units

Models

➡ **Neuro-psychiatric Disabilities Unit, Worcester, Massachusetts, USA**

This 10-bed unit is an acute adult psychiatric unit housed in a major medical centre. People must meet emergency psychiatric admission standards and pose a danger to self or others, including medical and self-care risk. The length of stay is ideally 10 days to two weeks (due to health care insurance company policies in the United States). Individuals may be referred by a case manager from the state Department of Mental Retardation, through service agreements with the START program (previously discussed in the Specialized Community Crisis Stabilization Residential Services section above), or referrals may come from private practitioners, emergency rooms, or families. Periodically, people are admitted for adjustment of psychoactive medications because they can only be managed safely within a 24-hour supervised medical setting.

The core treatment team includes a psychologist-program director, a Master's level clinical nurse specialist, a medical director who is also the attending psychiatrist, a primary care physician consultant, behavioural specialist, clinical social worker, and occupational therapist. People who present with significant medical needs, suicidal risk, or who are at risk for assaulting other patients may be assigned 1:1 staff (a mental health counsellor who will monitor and assist the individual, remaining within close proximity at all times.) The unit has a structured day program, mainly in the form of group sessions that occur from early morning until evening. Everyone is expected to participate in the sessions unless they are not able to do so (Charlot, Abend, Silka, et al., 2003).

An important goal for the unit is to provide holistic treatment. Most clients require multi-modal treatment with a combination of pharmacotherapy, medical treatments, behaviour modification, milieu therapy, family support, and systems interventions. Discharge planning begins the day of admission and direct participation of the community support network is required.

Specialized Tertiary Care

Description

Tertiary inpatient services provide assessment, treatment, stabilization, and secure placement for the most complex and refractory individuals with developmental disability and mental disorders with challenging behaviours. The literature outlines three distinct types of specialized tertiary care services for this client population:

- Comprehensive assessment, treatment, and stabilization unit with a maximum length of stay of less than 90 days;
- Intensive stabilization unit with a maximum length of stay of 90 days to two years; and
- Long-term stay secure units with a length of stay beyond two years.

Models

➔ Admissions Less than 90 Days:

Provincial Assessment Centre (PAC), Burnaby, British Columbia-Inpatient Service

The Provincial Assessment Centre, in Burnaby, British Columbia, is a provincial tertiary care service for people age 14 and up with developmental disabilities and concurrent mental disorder and/or challenging behaviours. PAC (formerly Willow Clinic) is a designated provincial mental health facility under the *Mental Health Act* administered by Community Living BC (CLBC).

CASE EXAMPLE 2

Aggressive behaviour in a medically fragile client with significant concurrent medical problems and no suitable treatment milieu

A 10-year-old boy with a developmental disability had numerous surgeries due to congenital heart disease, associated hemiplegia, and seizure disorder. Concomitant severe aggression to others was the main identified problem, along with self-injurious behaviour, hyperactivity, short attention span, sleep disturbance, and autistic features. He had access to behavioural therapy and respite from the family home, and a history of being unresponsive to or developing side effects from psychoactive medication trials. He was assessed by two psychiatrists, who noted that "He doesn't fit into any of the settings we have. His medical problems mean that he really couldn't fit into the ward programs." Three weeks later, he had an emergency admission to a child and adolescent psychiatric emergency unit, with aggression stated as the reason for the admission. This was followed by two subsequent admissions to an adolescent ward. This child required longer admission in a specialized unit, but no such unit was available. The treatment team needed to assess medication response and the child's behaviour away from the family home. His family needed more intensive assistance with behaviour management.

This program provides comprehensive assessment, treatment, and support services through multi-disciplinary staffing, including specialized nursing and psychiatry specialists, as well as access to medical specialists. The staff is highly skilled in managing behaviours across a wide range of clients. The services include a structured day program with a focus on basic life skills and therapeutic activities.

Client admission criteria are based on defined developmental disability status, as assessed by CLBC. A confirmed discharge plan and a return placement are part of the admission criteria. Individuals who are medically fragile are evaluated on a case-by-case basis. Requests for admission are reviewed on a weekly basis by the PAC administrative team.

Once treatment (behavioural, medical, and psychiatric) is completed (services may range from two weeks to a maximum stay of up to 90 days), clients are discharged back to the community. Prior to discharge, a planning meeting is held to share knowledge and treatment plans with direct support professionals, family members, and community stakeholders.

Medium to Long-term Admissions:

Dual Diagnosis Program Inpatient Unit – Toronto, Ontario

The Centre for Addiction and Mental Health (CAMH) in Toronto, Ontario operates a specialized tertiary care Dual Diagnosis Inpatient Unit for individuals with a developmental disability, mental disorders, and challenging behaviours within the Toronto area. This 15-bed program offers a continuum of specialized psychiatric and behavioural stabilization services. Access to the unit is through the community teams. The unit is small and aims for a length of stay of six months to a year. It serves individuals who could not be managed in the community or acute care services.

The program offers a day treatment service within the inpatient unit and accepts people from the community as an alternative to acute care inpatient admission. The day program offers assessment, time-limited treatment, and skill training. Access to this service is through the specialized community mental health teams. Close links with residential and community supports are maintained, as well as with family, friends, advocates, and local teams.

Weston Unit (Guy's Hospital, London) and MIETS (Bethlem Royal Hospital, Kent)

These units are associated with the greater London intellectual disability services. The Weston Unit is a short-term inpatient unit in the psychiatric wing of a large, metropolitan teaching hospital (Guy's Hospital) in southeast London. Referrals to the unit are initiated by one of three collaborative community developmental disability mental health teams. The unit provides comprehensive assessment of people with developmental disabilities and mental disorders living in the London area, and makes

recommendations to implement therapeutic interventions to ensure appropriate care. Close links with residential and community supports are maintained.

➔ Admissions Requiring Longer Term:

The Mental Impairment Evaluation and Treatment Services (MIETS)

This unit is at the Bethlem Royal Hospital, Kent, just outside London. It is a long-stay unit beyond two years that offers multidisciplinary assessment and treatment for people with mild to moderate developmental disability and severe mental disorder that prevents clients from living in the community. Frequent reasons for admission are serious aggression, sexually challenging behaviour, and fire-setting, and most people admitted have had contact with the criminal justice system prior to admission. A new building was recently constructed for this program and is a freestanding contemporary facility that allows for private and double rooms, multiple common areas, an inner courtyard, and a fenced outer recreational area. Treatment is based on the principles of sequential single hypothesis testing and functional analysis. Therapeutic interventions may include behavioural, pharmacological, psychological, and/or social interventions. The long-term goal of admission is to return the person to the community. The team works extensively with the community network to eventually prepare for discharge and to find the most appropriate community home that will maintain the individual to live successful in the community. (Xenitidis, Russell, & Ward, et al., 1999).

The Continuum of Community Services

As institutions have closed for people with developmental disabilities, a continuum of care and support has developed in communities, including:

- individualized care planning and support facilitation
- community living services (family and community support services, child services, residential care, day activities)
- generic community services including school, public health, child and family services, recreation, income assistance, employment and non-governmental community supports
- self-help, mutual aid, and advocacy

These services are needed to support a parallel continuum of mental health services¹³, and are illustrated in the diagram on page 29.

¹³ See page 30 for a discussion of the Mental Health Services Continuum.

As these services moved from institutions to the community, they have been developed in conjunction with a human rights perspective, recognizing the right of the person with a disability to be included in community and not marginalized. There are many individuals in the community who are not part of the service system, the majority of whom do very well if they have support of family, friends, community, and their family physician.

Individualized Care Planning and Support Facilitation

Increasingly around the world and in post-institutional service systems, service providers have come to appreciate that individuals with developmental disability can live successfully in the community with appropriate coordinated community services. The models of service coordination and brokering have changed over time. Some models feature individualized planning and support by professionals trained in life facilitation. In 'person centred' planning, both funded and unfunded supports are negotiated to achieve what is important to the individual.

A traditional model of management requires a case manager to follow the person through the system of care. If the person has a mental health problem or disorder as well, this case manager will maintain the key role in coordinating and linking the individual, family members, and residential and day supports with mental health services. In some jurisdictions, the case manager serves a long-term function once the person is identified for services.

Community Living Services

Family and Community Support Services

Formal family support programs are a key part of developmental services. Unlike individuals with only mental health and/or substance use disorders, many individuals with developmental disabilities remain dependent on others throughout their lives. With the move away from institutions, families may be lifetime care providers for individuals with developmental disabilities. Thus, families require a variety of enabling support services as well as information, training, and self-management tools to enhance their ability to support their family members.

Self-management tools for families include information on appropriate and effective treatment and support. They help the family cope effectively with stress and the challenge of distressing symptoms, and to learn about causes and risk factors. Without such supports, many families may be confused and overwhelmed by the complex, and at times conflicting, treatment recommendations of different service providers. They may miss appointments and fail to follow up with needed services. For many families, enabling services are necessary to ensure optimal medical outcomes. Such services

can include respite care¹⁴, transportation to appointments, contact with other families who have children with similar disabilities or conditions, counselling, and assistance with care coordination. Family support begins in childhood and may need to be life-long.

Child Services

Individuals identified as having a developmental disability may need lifelong specialized supports. If needs are identified before age three, they are termed “early intervention” services. These consist of developmental, occupational, speech language, and physical examinations. Services may be provided in the home by an infant development worker or rehabilitation therapist, or at a centre-based day service, depending on facilities in the community.

With the closure of many institutions for people with developmental disability in various jurisdictions, much headway has been made to develop inclusive communities where children with disabilities have full access to schools and community recreational activities. As the child reaches school age, a special educational plan is developed and maintained until the child’s 18th or 19th birthday.

Residential Care and Supported Housing

With the end of institutionalization of people with developmental disabilities nearing throughout the world, ideal residential care and supported housing are seen increasingly as normalized and integrated into the community. Persons with developmental disabilities may have a variety of living arrangements. They may continue to live with their families or live in the community in their own apartment, with a few hours of daily support from a professional community living support worker. They may live in a private home with an individual adult caregiver or family, or in a small group home with a few individuals.

Community-based residential services for adults promote community involvement, utilizing local services and resources and participation in community.

Day Activities

When individuals with developmental disabilities end their school years, the adult service system is the next step for community supports. These services vary in many jurisdictions depending on eligibility criteria for adult services as well as availability

¹⁴ Respite is provided for families and caregivers for individuals requiring 24-hour care. Emergency respite may be needed to address emergent crises and to prevent family or placement breakdown.

and suitability of services. Adult services are voluntary and may include vocational training and supports and day activity programs.

Range of Generic Community Services

School

School-aged youth and adolescent services provide team-focused planning for school-aged youth and adolescents. The team includes therapists, social workers, psychologists, recreation and leisure specialists, along with transition planning to adult services. Liaison teachers assist parents/caregivers with the placement, acceptance, and integration of students into a community school.

Special education and respite programs offer unique specialized teams for school, liaison teachers, and out-of-home respite. These programs provide an educational-therapeutic placement for kindergarten and primary-aged children with a primary diagnosis of a physical disability (neuro-motor) and associated complex communication, developmental, and/or learning disabilities.

Assistive technology programs provide specialty technology services such as augmentative communication. Equipment and support is available for individuals who have severe difficulty speaking or writing and who require augmentative and alternative methods of communication.

Transition programs, often at the community college level, are designed for youth leaving high school and consist of supported work experience, supplemented by small group instruction in academic subjects, language, pre-vocational skills, and social interaction.

Public Health

For specific high needs populations, such as children with Autism Spectrum Disorders, early intensive intervention programs target social skill building and communication. Early intervention programming provides supplemental clinical therapy to children who need additional help with speech and language development, behaviour issues, or sensory integration.

Seating and mobility programs provide systems that meet the complex medical, positional, and functional needs of children and youth, allowing them to increase their ability to participate in home, school, and community activities. Technical services promote and facilitate the use of computers, adaptive equipment, and adapted toys.

Child and Family Services

Parent and family support programs assist families through parent training, home visits, and support groups. The goal is to establish effective routines and work on specific, mutually agreed-upon goals.

Infant development programs provide prevention and early intervention service for infants and young children from birth to age five who have a physical and/or developmental disability or are at risk of a developmental delay.

Early childhood programs are intended for children from birth to school entry. These services offer assessment, treatment, consultation, and education from specialists such as physiotherapists, occupational therapists, speech-language pathologists, social workers, and psychologists.

Preschool services provide a therapeutic program for children who have physical disabilities and complex associated difficulties.

Behavioural support services provide care for children, youth, and adults with developmental disabilities requiring behavioural intervention and their families.

Recreation

Recreation is important both for building social networks and in improving fitness, self-esteem and confidence. Organized sports programs and events specifically for people with developmental disabilities, such as the Special Olympics (<http://www.specialolympics.ca/>) with its motto “winning at life,” exemplify these goals. Community-based recreation programs can become accessible for people with developmental disabilities with minor accommodations or individual support.

Income Assistance and Employment Support

Pre-vocational and vocational preparation programs provide learning experiences ranging from basic communication, daily living and work preparation skills to functional academics, clerical skills, and community-based work/study programs. Employment opportunities can range from secure, centre-based work (such as collating or assembling mailings), to supported employment (jobs in the community, supervised by a job coach, that require repetition, attention to detail, and adherence to routine), to competitive jobs (frequently awarded when a participant in a supported job demonstrates the ability to work independently).

Self-Help, Mutual Aid and Advocacy

Self-help can mean either helping oneself *without* the assistance of others or helping oneself *with* the assistance of others (*Review of Mental Health Reform*, 1997 p74). Self-help and peer support (among ‘consumers’) can enhance quality of life, improve

What is needed to support the formation of self-advocacy groups?

People with developmental disabilities who wish to form a self-advocacy group may face many barriers. They need recognition of their aspirations, information about self-advocacy, and support to accomplish the initial tasks. They must identify a meeting place, find ways of communicating with other potential members, and deal with transportation problems. Typically, they need allies to help them overcome these barriers, but these allies may be difficult to find. Almost always, self-advocacy groups are assisted by non-disabled helpers, often called advisors, allies, or interveners. These allies, who can be citizens, parents, or disability agency staff members who understand the importance of self-advocacy and who are willing to help, can assist with many of the tasks in forming a group (Shoultz, B., Center on Human Policy, The Arc of the United States <http://www.thearc.org/faq/samove.html>). See also the British Columbia Association for Community Living (<http://www.bcaccl.org>).

ability to cope with daily life, and promote relationships where respect, trust, and warmth can develop. Such outcomes contribute to improved self-esteem and the ability to make changes and good life decisions (adapted from the Ministry of Health *Peer Support Resource Manual*, 2001, at http://www.healthservices.gov.bc.ca/mhd/pdf/Peer_Support.pdf).

Similar to the term “consumer”, the term *self-advocate* is often used in the developmental disability community to describe a person with a developmental disability and others may use the term to describe themselves. The self-advocacy movement among people with developmental disabilities began in Sweden during the 1960s. Over the last 40 years, non-profit organizations, service agencies, and government operated developmental disability services have supported self-advocacy for people with developmental disabilities, often providing support and funding to attend conferences and meetings or help with designing web sites. There are many active self-advocates and some organized groups in the community. An example of an active self-advocacy group is *People First* which is an international self-advocacy organization, that focuses on building community involvement, lobbying for social change, establishing friendships, providing education about individual rights, and educating the community about their abilities and concerns. See <http://www.bcpf.bc.ca/> for more information.

In BC, a self-advocacy group that has a very innovative website is *SelfAdvocateNet*. See <http://www.selfadvocatenet.com/> for details.

Advocacy

Parents of children with developmental disabilities often meet other parents of children with similar needs, and informal or formal support groups often develop from these relationships. These support groups give parents the opportunities and skills they need to make effective changes and to advocate on behalf of their family members with disabilities.

Parents and associations for community living, provincially and nationally, have been leaders in advocacy for children, youth and adults with developmental disabilities, and have developed concepts such as a ‘Circle of Support’ that involves assembling a personalized network to support individuals and to promote community inclusion. Other family advocacy groups support efforts to develop disability tax credits, improve estate planning, and establish discretionary trusts that will enable independent community living after the death of the parent.

There is also strong interest in the development of *individualized funding* (IF) options, which connect funding to the person and services that best suit the individual. Individualized funding requires that the individual has family involvement or a

*microboard*¹⁵ to handle the administration of the funding, contracts, and hiring of staff. Microboards are an effective way to build support services around an individual with a developmental disability. A microboard is a non-profit society responsible for arranging and managing individualized supports and services, including managing contract funds.

Partnerships between community-based advocacy groups and government to promote improved health care for people with developmental disabilities can result from shared concerns. A good example in BC of such a partnership is the collaboration between the BC Association for Community Living and the provincial government's Ministry of Health, on a document about medical advocacy titled *Right to Health Care—Securing Health Care Access for Persons with Developmental Disabilities* (September 2000). This document, primarily for clinicians, suggests ways for family and community members to work in partnership with physicians and hospitals to gain equitable access to health care for people with developmental disabilities.

Government can help citizens in a collaborative fashion by providing formal support to promote positive advocacy. Many jurisdictions have independent advocates to help mediate and problem solve around complex needs. For example, in BC there is an Office of the Advocate for Service Quality, which is funded by the Ministry of Children and Family Development and which reports directly to the Minister. (http://www.mcf.gov.bc.ca/getting_help/advocate_service_quality.htm).

In addition, the Office of the Public Guardian and Trustee in BC can be called upon to help in situations relating to consent, substitute decision making, committee of person or property, and adult guardianship concerns for any vulnerable adult. (See pages 81-82 for further information about adult guardianship legislation in BC.)

In BC, Community Living BC incorporates advocacy into its governance provisions with strong representation of individuals with developmental disabilities and families on the Board of Directors, as well as an Advisory Committee to the Board comprised entirely of self-advocates (<http://www.communitylivingbc.ca>).

Another example of a government advocacy approach is the Alberta Premier's Council on the Status of Persons with Disabilities which was formed in 2002. The aim of the Council is to improve the lives of persons with disabilities by listening and compiling issues raised by the disability community and communicating them to

¹⁵ *Microboards are usually composed of 3-5 board members, including friends and family who serve on a volunteer basis. The board members know the individual well and consult with various care providers to make the best choices and arrangements for the individual. Microboards have been found to be effective and promote consistency in the implementation of individualized support plans.*

ministries and elected members of government.

(<http://www.seniors.gov.ab.ca/css/odi/>).

Universities can also play a role in supporting advocacy via the improvement of knowledge, policies, and practice related to the lives of persons with disabilities and their families. See, for example, the stated goal of the Institute on Disability at the University of New Hampshire, at <http://iod.unh.edu/welcome.html>.

Designing Effective Services for Individuals with Developmental Disabilities and Mental Disorders

General principles in designing services for this client population include:

- access to services
- appropriateness of care
- accountability of care (Beasley, J. B., 1997).

Access to Mental Health and Addiction Services

Access is the key element of all health services, for without access, there is no service. All mental health and addiction services must be inclusive, timely, and community based, including mental health and addiction services for people with developmental disabilities. Access to high-quality services is directly related to the ability of people to cope with difficulties and avoid prolonged suffering and loss of functional abilities. For example, access to mental health service providers who are trained in developmental disability and mental health and addiction ensures that effective diagnosis and treatment planning can take place. Access to service providers who are inexperienced and untrained can lead to meaningless or even harmful care (Beasley, 2000; 1997).

Early access to needed services and early intervention may lead to a decreased use of more intensive and expensive services later on. For example, if a person with a developmental disability experiences a major depressive episode, early treatment and intervention with a skilled mental health provider may avoid more serious outcomes, including self-injurious behaviour or health risks such as weight loss or sleep disorders.

Access to care is defined by the ability of an individual to receive care when and where they need it. For example, if an individual is in acute psychiatric crisis and needs a brief inpatient admission, this service should ideally be available in the individual's local community. Inpatient care should not be denied because of a client's disability.

Access to mental health and addiction services for people with developmental disability must include a range of resources to ensure that the most appropriate (least restrictive) and cost-effective services are used. During a time of crisis, if an individual does not require an inpatient admission, alternative services must be made available to help the individual and his/her support system to stabilize the acute episode without an inpatient stay. For example, the use of a partial hospital program maintains the person in his or her home (Luiselli, Lisowski & Weiss, 1998). Access to care also refers to the community safety net which must be available in order to prevent the unnecessary readmission to hospitals or institutions.

Access is also measured by the time it takes to get help when needed, and whether or not individuals get what they want when asked. Coordinated care models focus on ready access to services.

Appropriateness of Mental Health Care

Appropriateness of care is reflected in the ability of mental health service providers to meet the specific needs of an individual. This is perhaps the most difficult element for health planners to implement. Rigorous standards of excellence in diagnosis and treatment of mental disorders for people with developmental disabilities must be used. Service need is determined by accurate diagnosis and treatment planning combined with careful consideration of how particular services affect the quality of an individual's life. There must be an effective range of mental health and addiction services available.

To be effective, service planning and delivery must be coordinated at the individual, program, and system levels. The goal is to build a network based on a continuum of integrated services and supports (Dart, Gappen & Morris 2002).

The service system must be able to provide ongoing training, consultation, assessment, and treatment. Quality of service requires a commitment to staff training and incentives. There must be a high level of awareness of the latest evidenced-based information on treatment interventions and associated mental health issues by direct support staff, and a way to disseminate effective training modules in interdisciplinary practice. Training must include information appropriate for social workers, nurses, physicians, psychologists, behaviour intervention specialist, family members, peer support workers, individuals with a developmental disability, direct support professionals, job counsellors and other frontline support staff.

Services must occur as part of a comprehensive integrated system-wide plan. Systems of support must integrate horizontally to avoid fragmented planning and delivery of services.

By utilizing the *horizontal service linkage* approach to coordinated service delivery, service linkage teams promote interdisciplinary treatment planning and service delivery, while clarifying each member of the system's role in the ongoing provision of mental health care (Beasley & Kroll, 2002). Horizontal linkage services often include consultation, training and service planning and development. In some cases additional services are provided to fill in existing service gaps; however, the mission is to facilitate coordination and improvement in existing services. Therefore, most of the services utilized in the context of a horizontal service linkage system are independent of one another both administratively and fiscally. Unlike traditional case management, the models using the service linkage approach often have affiliation agreements or protocols that are negotiated administratively between systems rather than based on individual service needs alone. This is the predominant approach used by program

models found in North America and Europe to improve the mental health care of individuals with developmental disability (Bouras, Holt, Murphy, et al. 2001).

It is important to recognize that no single service or individual alone can achieve the goal of developing a support network, nor can a network be established through any single process or method. What is needed is an approach that ensures coordination among various stakeholders. Both formal and informal services and supports must be involved in the development of the network, with formal service agreements signed by network participants outlining the specific services that each will provide (Dart, Gapen & Morris, 2002).

Professionals involved must be willing to serve all individuals regardless of the level of developmental disability and the extent of the psychiatric impairment. A program designed to serve individuals that easily “fall through the cracks” in the system cannot be selective when choosing a clientele.

In addition, there must be a consensus among professionals in the community that there is a need for a comprehensive integrated service program. Once a consensus is established, the community must provide cross-system access by employing staff who are experienced and respected by both the mental health and developmental disability systems (Davidson et al., 1999). Using an interdisciplinary approach promotes this cross-system access, along with development of multiple interventions that may be beneficial for individuals with a developmental disability and mental health needs. Finally, effective service provision for this population must be community based, because that is where most of the resources for this client population are found. By following these guidelines and the examples of programs already in place, service providers can ensure that individuals with developmental disabilities and mental health needs can receive specialized services by qualified professionals, rather than falling through the cracks of both the mental health and developmental disability systems of care.

Developmental mental health requires interdisciplinary assessment, understanding of developmental disabilities, and recognition of communication and behavioural issues. In some cases, behavioural change can be a means of communicating physical and psychological distress in those with limited communication skills. *Applied Behavioural Analysis* (ABA) treatment is an essential component of addressing behavioural and mental health problems in people with developmental disabilities (Luiselli, 1998; Gardner, 2002; Griffiths, Gardner, & Nugent, 2001).

In evaluating appropriateness of care, health planners must ensure excellence through careful attention to treatment approaches. It is possible, for example, to have excellent access to care without receiving appropriate care. Thus, an individual may have access to an inpatient facility quickly during a psychiatric crisis, but if the treating mental health team does not have an accurate diagnostic and treatment strategy, the services received will not be effective.

A recent review of research evidence focusing on treating mental disorders in children with developmental disabilities is provided in C. Schwartz et al.'s report *Mental Health and Developmental Disabilities in Children*, available at http://www.childhealthpolicy.sfu.ca/publications/index_gov.html

Accountability of Mental Health and Addictions Care

The third essential element for effective mental health and addictions service provision for this client population is accountability. Service systems must be accountable to everyone involved in the provision of care, and this includes funding sources. Outcome measures must be clearly defined, and review of data must be frequent and ongoing.

Quality improvement outcomes should be realistic, measurable, and demonstrate social validity. Services must be individual-centred, meeting the unique needs of individuals. Quality improvement outcomes are to be measured by an increase in quality of life rather than exclusively by a decrease in challenging behaviours or psychiatric symptoms. In addition, it is essential to recognize the central role of families and caregiver supports (Beasley J. B., 1997).

Services must be 'user-friendly' with adequate attention to literacy support strategies and cultural sensitivity. Systems must have a structure, which can readily adapt to changes in the demands which are placed upon them. (See *BC Partners for Mental Health and Addiction Information*, under Resources.)

Services must be cost-effective, while ensuring access and appropriateness. These three factors only conflict when attention to appropriateness of care and the need for access is lacking. Analysis of data must be used as a barometer of where a service delivery system has succeeded, and will guide further development of the system. Data should be multidimensional, and should include both qualitative as well as quantitative measures.

There is consensus among experts that a major barrier in better serving this client population is the challenge of allocating care responsibility between mental health services and developmental disability services. Inter-sectoral protocols and agreements between mental health and developmental disability services are the main route to overcoming this barrier.

In 2003, the Alberta Provincial Board for Persons with Developmental Disabilities and the Alberta Mental Health Board prepared a provincial partnership framework, which supports the development of inter-sectoral protocols and agreements between the two boards and their respective regional programs. This framework document is available at: http://www.pdd.org/docs/prov/partnership_framework.pdf.

The principles in this framework include the importance of accountability of care, appropriateness of care, and access to services. The document describes benefits of partnership frameworks and supporting protocols including increased capacity to address complex mental health and social issues that can elude a solution when handled by one organization only.

The Alberta Framework directs regional programs of both Boards to include individuals/ families/guardians as partners; to appreciate their diversity; and to emphasize cooperation, innovation, ease of access, sharing of resources, and innovation and excellence in practice.

Appendix 5 of the framework document describes regional partnership initiatives in Alberta. Appendix 6 outlines the terms of reference for a provincial Developmental Disabilities Mental Health (Dual Diagnosis) Steering Committee and describes its scope:

“Operating in an advisory capacity the committee will serve as a forum for coordinating the provincial implementation of the Partnership Framework, sharing successes and promising practices, addressing regional and provincial issues, monitoring progress and evaluating the success at the operational level.”

Quality Indicators

The development of quality indicators is fundamental in order to monitor the provision of mental health services for individuals with developmental disabilities and mental disorders. The dimensions below, based on the framework developed by the *Canadian Institute for Health Information* (CIHI), are recommended for measuring quality of services for this client population. Key quality indicators relevant to this client population include:

Accessibility

- timely access to mental health and addiction assessment and treatment services
- timely access to emergent mental health care
- family members’ perception of accessibility to family services and support, and
- access to physician care (physician with a specialty in psychiatry and developmental disabilities)

Appropriateness

- implementation of an accepted set of standards for the delivery of mental health services for individuals with developmental disabilities and mental illness

- existence of clinical information systems that effectively communicate information among key service providers
- existence of services and supports across the full continuum of services, and
- evidence of standardized assessment tools of client functioning

Acceptability

- individual and family perception of satisfaction of services, cultural sensitivity/safety (e.g. stigma, stereotyping etc.) and responsiveness, and
- practices compliant with the mental health act and other legislation

Meaningfulness

- clinical status (i.e. proportion of individuals experiencing significant reductions in the number and severity of symptoms)
- functional status (i.e. proportion of individuals with improved (or maintained) function as measured by standardized functioning instrument)
- quality of life improvement, and
- early mortality improvement in longevity

Continuity

- timely communication of assessment and treatment plans to community care services;
- existence of protocols between health services and developmental disability services, and
- proportion of clients receiving regular family physician services (e.g. annual physical examination)

Safety

- frequency and severity of critical incidents
- frequency of self-injury, and
- frequency of staff injury as a result of providing care

Efficiency

- practices and procedures in place to optimize efficient use of resources
- unit cost and cost per client, and
- evidence of use of distance technologies to minimize travel costs

Competence

- trained/educated staff to meet required competencies for role
- knowledge and skills in assessment and management, and
- provider perception of satisfaction with enrichment opportunities.

(See the Canadian Institute for Health Information: <http://www.cihi.ca>.)

Health Indicators and Health Disparities for People with Developmental Disabilities

The quote at right is from *Addressing Health Disparities through Promoting Equity for Individuals with Intellectual Disability* (Ouellette-Kuntz et al 2005), in which the authors review policy from outside of Canada on health indicators and disparities for people with developmental disabilities and reflect on the current status and gaps in Canada. The article focuses on disparities in the area of mental health, but also acknowledges the disparities in overall health care for this population. In Europe, the *Pomona Project*¹⁶ (2004), funded by the EU Health Monitoring Unit, has developed a set of 18 health indicators that cover physical and mental health needs for people with developmental disabilities.

The Pomona Project Health Indicators

The Pomona Project's set of health indicators include:

- **demographics:** prevalence, living arrangements, daily occupation, income/socio-economic status, and life expectancy
- **health status:** epilepsy, oral health, body mass index, mental health, sensory impairments, mobility
- **determinants:** physical activity, challenging behaviour, psychotropic medication use
- **health system:** hospitalization and contact with health care professionals, health check, health promotion, specific training for physicians

Ouellette-Kuntz and her colleagues point out that Canada—unlike the UK, USA, Scotland and the EU—has not yet developed a policy document to address the health and social disparities for people with developmental disabilities, and they call for a national agenda to make this a priority.

See http://www.cihr-irsc.gc.ca/e/documents/Volume_96-S21.pdf for more on health disparities in Canada.

Also of interest:

“Given that appropriate health care leads to better quality of life for individuals, and that to be effective in obtaining this health care individuals must have the ability to express their health concerns and problems, persons with developmental disabilities are at a distinct disadvantage: they often do not have the communication skills that allow them to articulate their health needs, and health care professionals usually do not have the skills to obtain the necessary information to enable diagnoses. For most individuals with developmental disabilities, their health care needs are determined by proxy, by family members or caregivers who best know the individual and by health care professionals who are often unfamiliar with the individual. As a result, both access to and utilization of health services are limited and thus persons with developmental disabilities do not have optimal quality of life” (Ouellette-Kuntz et al., 2005).

¹⁶ See <http://www.pomonaproject.org/report.php>

Closing the Gap

<http://www.nichd.nih.gov/publications/pubs/closingthegap/index.htm>, USA

Valuing People

<http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>,

UK

Review of Access to Mental Health Services for People with Intellectual Disabilities

http://www.nda.ie/_80256F4F005C7F9E.nsf/0/815EB07591494D9D80256F62005E6964?Open&Highlight=2,review,of,access,to,mental,health,services, Republic

of Ireland

These publications are also listed in the Resources Section of this document under *Government Publications: USA and European*.

CHAPTER 3: Description of Programs and Services

Integrated Versus Specialized Services

The topic of specialized versus integrated services has been discussed by various authors in their reviews of services for this population. Findings within the literature confirm that:

- Complex behaviour problems of people with severe developmental disabilities require specialized knowledge and intervention.
- Attempts to integrate specialized developmental disability services within mainstream generic psychiatric services have been very challenging and often been unsuccessful, confirming that most clients could not be handled by generic psychiatric services alone.
- Specialized interdisciplinary mental health service teams for this client population have been found to be a more effective service model. This arrangement provides not only the needed expertise, but also a bridge between the health care and social services sectors.
- These specialized mental health service teams allow for the development and sharing of new knowledge and expertise in the areas of specialized assessments, treatment, ongoing support, including managing challenging behaviours. This in turn supports research and evaluation of clinically effective practices.
- It is essential that strong linkages be established with the specialized teams and generic mental health services to facilitate the use of established mainstream mental health services such as emergency and inpatient services.

In *Building Resource Systems for Persons with a Dual Diagnosis* prepared by the Developmental Consulting Program at Queens University (2001), the authors provide a section dedicated to this discussion. The following quote summarizes their key points.

“The presence of dual diagnosis (developmental disability and a mental health disorder) is often associated with the breakdown of community placements and retention in residential environments that are more restrictive than otherwise required (Bouras & Holt, 2000, Davidson et al., 1995). Behavioural or psychiatric disorders that may have been accepted in institutions are not manageable in community placements. Consequently, individuals with dual diagnosis need treatment and social support if community-based care is to be successful. Over the past twenty years, policy makers and researchers have been struggling to develop comprehensive models of service that combine best practices and evidence-based treatment (Bouras and Holt, 2000). Whether to provide specialized treatment services or to integrate those with dual diagnosis in mainstream mental health services is a recurrent theme. A UK expert (Day, 1993, p. 7) has concluded that attempts to ‘provide for mental health needs of people with developmental disabilities within generic psychiatric services, whether by design or default, has been obviously unsuccessful.’ Bouras and Holt (2001, p. 400) have observed that the complex behaviour problems of people with severe developmental disabilities could not be handled by generic psychiatric services and that no attempt was made to negotiate the associated service issues between mental health and social service providers.

There is now published opinion on how to best resolve the issue of specialized vs. generic provision of care. According to the Mansell Report (UK Department of Health, 1993), the aim of service planning should be to ‘develop and expand the capacity of local services for people with developmental disabilities, to understand and respond to challenging behaviour’ and to ‘provide specialized services locally which can support good mainstream practice as well as directly serve a small number with the most challenging needs’ (p.17). North American contributors (Davidson, et al., 1995; Gopen et al., 1996) emphasized that specialized interdisciplinary mental health services should be available in local communities; this arrangement provides not only needed expertise, but also a bridging between the health care and social services sectors. There are also other clear advantages in establishing specialist support services.

Given the frequent exclusion of challenging individuals from services, such developments clearly demonstrate commitment to serving the client group. Moreover, they also allow for the ‘accumulation of knowledge and the development of expertise in managing challenging behaviours, which can act as a focus for research and development of clinically effective practices, and also serve an advocacy function’ on

behalf of individuals with mental health needs and/or challenging behaviour (Allen & Felce, 1999, p.285).

With a growing consensus on both sides of the Atlantic that the optimal approach involves the availability of local expertise and good coordination of effort between the health and social services sectors, there is an obvious need to consider how much expertise is required and how best to ensure good coordination between agencies. The UK survey by Bailey and Cooper (1997) is useful from this perspective, in terms of both the desirable size and composition of local teams and the optimal number of treatment beds required to serve those needing specialized inpatient care. The survey canvassed NHS Trusts in England and Wales (i.e. agencies providing care to persons with developmental disabilities) to establish the number of professionals assigned to community care per 100,000 population.

Achieving coordination of effort between sectors can be enhanced simply by providing locally accessible (vs. regional) mental health services. Linkages to generic mental health services facilitate the use of established emergency and inpatient services and coordination of effort with other hospital services (e.g. x-ray, laboratory, EEG, etc.). With this kind of help, local social service agencies can count on the available expertise of nearby mental health service providers, and at the same time improve their own skills in serving persons with dual diagnosis (Bouras and Szymanski, 1997)."

In Ontario, providing treatment for persons with dual diagnosis is now regarded as "specialized" or "tertiary" care. (Government of Ontario, *Making it happen*, 1998). However, it is also observed that such care is not necessarily long-term or regionally provided; indeed, the optimal arrangements involve the provision of localized expertise and integration, insofar as this is possible, of secondary and tertiary levels of care (Wasylenki et al., 2000).

Examples of Services Delivering Secondary Mental Health Care, Community Mental Health, Emergency Response and/or Inpatient Care

Some programs are regarded as models for efficacy of service development and delivery. Each model program described below includes several components of secondary care and has a strong program that works collaboratively with the community. This list presents several types of service provision and is not inclusive. The programs described here provide a small sampling of what exists.

Dual Diagnosis Programs, Toronto, Ontario

The program hosts a specialized community team: the Dual Diagnosis Resource Service –Toronto. This service offers time-limited consultation, assessment, diagnosis, and treatment, as well as in-home and crisis supports, program recommendations, training, advocacy, and coordination among services offered by different agencies. The Dual Diagnosis Resource Service has active partnerships with the Griffin Community Support Network and COTA-Comprehensive Rehabilitation and Mental Health Services - Specialized Dual Diagnosis Case Management Service. The staff team includes psychiatry, psychology, social work, nursing, and occupational therapy professionals and a research assistant.

The program also offers a day treatment service for patients on the inpatient unit, and it accepts community clients as an alternative to inpatient admission. The day program offers assessment, time-limited treatment, and skills training. Access is through community teams.¹⁷

The Dual Diagnosis Service-Peel Region is a second smaller team hosted by the program. This service offers consultation, assessment, diagnosis, time-limited treatment, crisis planning, program recommendations, education, training, advocacy, and coordination and facilitation among services. This service is offered through a partnership with the Housing and Support Program in Peel, which provides access to a limited number of supported independent living units for individuals with a dual diagnosis. The staff team includes social workers, housing support workers, and part-time access to psychiatry and psychology.

The Dual Diagnosis Program at the Centre for Addiction and Mental Health (CAMH) has been developed based on a cross-sector collaborative and integrated service model, achieved through a variety of mechanisms. It reflects the integration of mental health and developmental perspectives and the biopsychosocial approach to care through the hiring of a multidisciplinary staff team. The service is focused in the community, with admission to the inpatient unit as a last option. Service is delivered based on an interdisciplinary team approach. Written contracts are utilized both with the outpatient services and inpatient/day treatment admissions to ensure a cross-sector approach, clarity of expectations and time lines, and planned discharge routes. Therefore, there is an

¹⁷ *Toronto also established a specialized tertiary Dual Diagnosis Program inpatient unit within a psychiatric hospital. See the Tertiary Mental Health Care section for more details.*

emphasis on shared team work with community providers, documentation of the assessment and treatment services incorporating the biopsychosocial perspective, and shared ownership with clients, families, and community providers from the point of referral through to discharge.

Active partnerships are established through formal written agreements with community programs in the developmental and mental health sectors to address access to crisis services. This wrap-around approach supports the transition of long-stay inpatients to residential care homes, and facilitates access to specialized dual diagnosis case management and specialized psychiatric consultation, as well as to specific programs within CAMH (e.g. Personality Disorders Program, Emergency Room). Additionally, cross-appointments to the Department of Psychiatry at the University of Toronto support growth in teaching and research activities.

The Griffin Community Support Network (GCSN), besides the links described above with the Dual Diagnosis Program, is also directly linked to Toronto's Coordinated Crisis Services. The GCSN provides time-limited crisis and transitional support to individuals aged 16 years and over with developmental disabilities. It offers a range of safe bed sites, as well as time-limited supports that include day activities, telephone support, mobile crisis services, service coordination, in-home support, out- and inpatient services, and access to a range of specialized consultation and treatment services (Dart, Gapen & Morris, 2002). The goal of the Network is to develop creative, collaborative community-based strategies to provide a range of accessible, flexible primary and specialized service options to youth/adults at risk of frequent hospitalizations, incarcerations, or homelessness, or to those who have had difficulties being served by the system. The Network represents a convergence of resources across systems and incorporates the flexing and reallocation of funding so as to respond to the unique requirements of individuals with complex needs (Carson & Dart, 2003). The GCSN represents over 50 partnering agencies working collaboratively through an arrangement of formalized partnerships whose services may be funded at a municipal, provincial, or federal level.

Mental Health Team in Developmental Disabilities, Kingston, Ontario

In Kingston, a Mental Health Team in Developmental Disabilities has been established. It comprises a multidisciplinary team of professionals, including a psychiatrist, social worker, and psychologist who work exclusively with individuals with dual diagnoses. The core members of the Team are faculty of the Department of Psychiatry, Faculty of Health Sciences at Queen's University. Their positions were created in order to conduct research/teaching as well as to provide part-time community service.

The Mental Health Team in Developmental Disabilities offers its services to individuals with a dual diagnosis on both an inpatient and outpatient basis. Included in this population are individuals with Pervasive Developmental Disorders who may not necessarily have an intellectual impairment, but have psychiatric or behavioural disturbances. Inpatient services are provided at Hotel Dieu Hospital's psychiatry ward, whereas outpatient consultations are provided through the Department of Psychiatry's Ambulatory Clinic located on Barrie Street.

Referrals to the Mental Health Team are either received internally from members of the faculty of health sciences or through admissions from the Emergency department of Hotel Dieu Hospital, or externally from a variety of community referral sources including self-referrals, family physicians, community-based organizations serving individuals with developmental disabilities, Assertive Community Treatment Teams, Adult Protective Services Workers, and Probation Services. Members of the Mental Health Team offer varied services including psychiatric assessments, psychiatric medication reviews, social support assessments, consultations with families or care providers regarding the identification of community-based supports, individual therapy, diagnostic assessments, functional assessments of problem behaviours, transition planning consultations, treatment development and planning, and long-term planning.

The Rochester Community-Based Crisis Intervention Services, Rochester, New York, USA

The Rochester Community-Based Crisis Intervention Services is a university-based program. Services include establishing formal and informal communications and agreements among various providers, educating families and agency staff (e.g. psychiatric and emergency room staff, social workers, and physicians), conducting skilled behavioural assessments, and employing positive behaviour support techniques. The Rochester outpatient clinic offers mental health services to individuals and families of individuals with developmental disabilities and mental health needs, and provides training for caregivers and clinicians in collaboration with the crisis intervention team. The program has had good published outcomes, including a significant reduction in the use of emergency and inpatient services (Davidson, Morris & Cain, 1999).

The START Model, Danvers, Massachusetts, USA

One of the first projects to follow the community model and the team approach was the START model outside of Boston, Massachusetts. START stands for Systemic, Therapeutic, Assessment, Respite, and Treatment, and it is primarily a crisis intervention and prevention service. The program is staffed by a part-time psychiatrist, three Masters-degree clinicians, six Bachelor-degree clinicians,

psychology consultants, and licensed social workers who act as consultants. The services provided include emergency assessments, respite care, and coordination of outpatient services for people with developmental disabilities who are experiencing acute behavioural and/or emotional crises. The program also provides education for care providers and clinicians regarding the mental health needs of people with developmental disabilities.

START is a program that intervenes when a mental health problem is suspected and remains involved with the individual to ensure proper services. The crisis clinician acts as consultant and case manager, pulling together the community team and working with health care, agency, and natural supports. The “case” is held active until the individual has fully stabilized. The clinician develops a written “crisis plan” that is developed collaboratively by the entire team and is signed off by each team member. By disseminating this crisis plan, the program ensures that everyone involved with the individual has the information available 24 hours a day.

The START program at the Robert D. Sovner Resource Center links developmental disability agencies and mental health providers serving the general population. The program also provides crisis intervention services and specialized outpatient psychiatric services for persons with developmental disabilities and mental health needs. Services include a mobile emergency team, cross-systems emergency consultation at psychiatric inpatient units or respite facilities, an emergency respite facility with emergency and planned respite services, and linkages with community general hospitals and psychiatric facilities that provide inpatient care. The program focus is the development of individualized cross-systems crisis prevention and intervention plans and flexible resources to provide specialty interventions as needed. (A more detailed description of START is provided in the Tertiary Care section below). The START program has a specialized agreement with an inpatient unit at the University of Massachusetts Medical Center in Worcester (described below in Tertiary Care). This 10-bed unit is an acute adult psychiatric unit that meets emergency psychiatric admission requirements, aiming for a 10-day to two-week stay.

The ENCOR Model, Eastern Nebraska, USA

The Eastern Nebraska Community Office of Retardation in Omaha, Nebraska, was designed two decades ago to promote community involvement and citizen advocacy for people with developmental disabilities and individuals with added mental health needs. Approximately 19 percent of the individuals with developmental disability served by ENCOR have a mental illness. The types of mental illness seen in this population include schizophrenia, personality disorders, and anxiety disorders, among other diagnoses (Fletcher, 1993). Clients served by ENCOR can be classified into three levels of involvement: Level I

includes people who present daily behavioural management problems; Level II includes people with occasional behavioural problems; and Level III includes people with infrequent behavioural problems. This classification does not make service provision dependent on a specific diagnosis; rather personnel, supports, and other services are determined by the level of a client's need.

ENCOR has a policy of zero rejection, which means no individual will be denied services due to the severity of the mental illness and/or developmental disability. In addition, ENCOR is committed to active treatment of people with mental health needs, and continually works to link professionals from local mental health and MR programs. ENCOR's services include family support, specialized group homes, crisis assistance programs, preschool services, in-home teachers, integrated job placements, and inpatient/outpatient care provided by psychiatric professionals (Davidson et al., 1999). The specialized clinical staff at ENCOR become involved in nearly every aspect of the client's life in order to provide the most effective services possible.

The Community Specialist Psychiatric Service, London, England

Another example of effective service is the Community Specialist Psychiatric Service (CSPS) in London. Initially, interdisciplinary teams were formed by England's National Health Service to support people with developmental disabilities in the community, but plans for mental health services for these individuals were not made until the development of CSPS, which provides clinical and consultative services. A CSPS clinician becomes involved with the team if a mental health diagnosis is suspected, and provides assessment, home-based support, outpatient care, and inpatient psychiatric treatment. In the consultative role, clinicians in this program provide not only expertise on developmental disability and mental health issues to the interdisciplinary teams, but also education to relatives, service coordinators, and other organizations. CSPS is an excellent example of a program that employs qualified clinicians to provide direct services to clients, while also educating and training other individuals involved in a client's life.

In London, two specialized inpatient programs are available for these clients. One small unit for more acute care is operated in London at the Guy's hospital, and the other operates outside London at Bethlem Hospital, which is larger and treats more long-term care needs. (Xenitidis, et al., 2004). These inpatient units are described in more detail in the Tertiary Mental Health Care section below.

The Interface Model, Cincinnati, Ohio, USA

The Interface Program was developed over two decades ago in Cincinnati, Ohio, to provide multi-system services to individuals with developmental disabilities and mental health needs (Woodward, 1993). Although the Interface Program is funded by the Hamilton County Community Mental Health Board, it is administered by the University Affiliated Cincinnati Center for Developmental Disorders, which removes primary responsibility from both the mental health and MR/developmental disabilities service systems. The Interface Program is composed of three dual diagnosis specialists and one coordinator, with responsibilities in the development and implementation of individualized service plans, provision of necessary mental health and MR services, maintenance of effective interdisciplinary team characteristics, data collection on dual diagnosis subgroups, and local and regional educational programs.

In addition to this team of specialists who pull professionals together to access necessary services for individuals with developmental disabilities and mental health needs, the Interface Program also provides crisis intervention services. Until the implementation of these services in 1986, individuals with mental health needs and/or challenging behaviour who were in crisis were often taken by police to the local psychiatric emergency service, which was not always equipped to serve them. As a result, a contract between the hospital and the Hamilton County Board of Mental Retardation and Developmental Disabilities funded three additional specialists to provide assistance seven days a week to hospital mental health professionals in serving individuals with dual diagnosis. This contract also provided for four short-term hospital beds exclusively for people with dual diagnosis.

The Ulster County Comprehensive Mental Health Model, Kingston, New York, USA

In Ulster County, New York, community agencies serving individuals with developmental disabilities worked together with the local mental health board to create a comprehensive plan that meets the needs of people with dual diagnosis (Davidson et al., 1999). The plan includes seven specific service components designed to meet the unique needs of this population. The outpatient mental health services are provided by the Dual Diagnosis Unit of the Ulster County Mental Health Department. They include assessment, diagnosis, treatment, case management, and consultation services. Day treatment services are provided by both the MR and mental health systems, and two local hospitals are responsible for acute psychiatric treatment.

Most residential services are provided by the New York State Office of Mental Retardation and Developmental Disability. There is one 12-bed group home for

individuals with dual diagnosis that is funded by the mental health department. Two local agencies provide vocational services, with options that include sheltered workshops and supported employment. Most importantly, the Ulster County model provides training in dual diagnosis to a wide variety of staff and helps to coordinate services in both systems through regular team meetings (Fletcher, 1993). Ulster County is able to provide effective services to individuals with dual diagnosis due to the substantial amount of effort in coordinating services between the two systems and encouraging professionals to work together to meet the needs of each individual client.

Montréal Centre Region, Montréal, Québec

The Program Régional d'Expertise Montréalaise en Troubles Graves due Comportement (PREM-TGC) is a project funded by the Montreal Regional Council of Health and Social Services. The Miriam Home and Services Rehabilitation Centre oversees a project while the Director of Development, Evaluation and Research, supported by a team of specialists in severe challenging behaviour, ensures its management. A steering committee, chaired by the management of Miriam Home and Services Rehabilitation Centre and composed of members of the health and social services network, provides counsel to the senior management of PREM-TGC, in matters of intervention and training.

Two steering committees—one for developmental disability and pervasive developmental disability and the other for traumatic brain injury—advise the intervention and training programs. The committees are chaired by the management of the Miriam Home and Services, and are composed of members from the health and social services network. This network serves people of all ages who present with severe challenging behaviours and/or mental disorders including developmental disabilities, pervasive developmental disorders, and physical and neurological disabilities associated with behavioural and psychiatric illness. The mission of the Regional Multidisciplinary Expertise Program for Severe Behaviour Disorders is to raise the level of expertise among professionals. Thus, the staff of organizations in the network receive consultation, intervention, and training. In the network, there are *rehabilitation centres*¹⁸ and psychiatric hospitals that can contact the team for consultation.

The services are all community based and include work with family and natural supports, as well as agencies, hospitals, and centres. Linkage to resources and the advancement of best practices are key goals. Any organization within the

¹⁸ Rehabilitation centres in Quebec are similar to community living associations, providing day programs, support workers, employment support, etc.

network can request a consultation. A Professional Opinion is submitted to the liaison agent/case manager at that organization and he or she gathers information about the severity of the problem, and may make recommendations about the referral. If necessary, as a second step, the liaison agent assists the treatment team in preparing a formal consultation with the treatment team.

The treatment team uses a collaborative data collection process to thoroughly understand the person's behavioural patterns and/or psychiatric disorder. Interventions may be suggested to the referring agencies and community support network. For example, a consultation with a family practitioner about the use of antidepressant medication may be useful and address the presenting problem. Further consultation may include specific interventions, professional evaluations, as well as medical or psychiatric assessment by specialized professionals in developmental disability. These specialized professional evaluations clarify the diagnosis and treatment plan using a multidisciplinary approach. Direct interventions may be behavioural or may involve medical and psychiatric care. If necessary, further help from the Joint Intensive Interventions Program improves the outcome and expertise in the partnership in the Montréal area.

Examples of Specialized Tertiary Inpatient Units

The following section describes several stabilization and assessment inpatient programs in BC, other areas of North America, and the UK that provide specialized care for adults with developmental disabilities.

Dual Diagnosis Program Inpatient Unit, Toronto, Ontario

Toronto established a specialized tertiary Dual Diagnosis Program inpatient unit within a psychiatric hospital: the Centre for Addiction and Mental Health (CAMH). The Dual Diagnosis Program at the Centre is a specialized program for individuals with a developmental disability and psychiatric/behavioural difficulties, their families, and care providers. The program offers a continuum of specialized services. This inpatient unit hosts 15 beds for time-limited admission, assessment and treatment. Access to the unit is through community teams. The unit is small and aims for a length of stay of six months to a year. It serves individuals who could not be contained or served in the community.

The program also offers a day treatment service for people on the inpatient unit and it also accepts people from the community as an alternative to inpatient admission. The day program offers assessment, time-limited treatment, and skills training. Access is through community teams. (This specialized inpatient unit is linked to the rest of the Dual Diagnosis Program in Toronto, described in the Secondary Mental Health Care section above)

Provincial Assessment Centre (PAC), Burnaby, BC - Inpatient Service

The Provincial Assessment Centre, on the BC mainland, is the current tertiary resource for people ages 14 and up with developmental disabilities and concurrent mental health needs and/or challenging behaviours in BC. PAC (formerly Willow Clinic) is a designated facility under the *Mental Health Act*. It moved from its former location to a new site in early 2005.

PAC is unique in that it is administered by Community Living BC (CLBC), and prior to that by the Ministry of Children and Family Development rather than the Ministry of Health. Requests for admission to PAC are currently initiated by CLBC field staff, community agencies, families, or community specialists, and are directed to the appropriate CLBC manager who gives regional approval for admission. All requests for admission are directed to the PAC Social Worker. Individuals who meet eligibility requirements for service from CLBC are eligible

for admission. Individuals are at times admitted by committal under the *Mental Health Act*.

To meet the eligibility criteria of both CLBC and PAC, intake information is reviewed on a weekly basis to determine admission suitability. These criteria include an inability to manage individuals within their families or within a community-based residential resource, consultation with a local Mental Health Support Team (including psychiatric consultation), and consideration of, and lack of success in, using community resources (Wand, R. 2002).

Admission to PAC is based on defined developmental disability status, as assessed by Community Living BC. A confirmed discharge plan and a return placement are imperative. Individuals who are medically fragile are evaluated on a case-by-case basis. Requests for admission are reviewed on a weekly basis by the PAC administrative team.

Once treatment (behavioural, medical, and psychiatric) is completed (admission may range from two weeks to a maximum stay of up to 90 days), clients are discharged back to the community. Prior to discharge, a planning meeting is held to share knowledge and treatment plans with direct support professionals, family members, and community stakeholders. A multidisciplinary team discharge report is provided.

Weston Unit (Guy's Hospital, London, England) and MIETS (Bethlem Royal Hospital, Kent, England)

These units are associated with the greater London intellectual disability services. The Weston Unit is a short-term inpatient unit in the psychiatric wing of a large, metropolitan teaching hospital (Guy's Hospital) in southeast London. Referrals to the unit must be initiated by one of three collaborative community developmental disability teams. The unit provides comprehensive assessment of people with intellectual disabilities and mental health problems living in the catchment area, and makes recommendations to implement therapeutic interventions to ensure appropriate care. Close links with residential and community supports are maintained, as well as with family, friends, advocates, and local teams. Admissions to general psychiatric units have been problematic in areas despite agreed-to protocols. (Xenitidis, et al., 2004).

The Mental Impairment Evaluation and Treatment Services (MIETS) facility is at the Bethlem Royal Hospital, Kent, just outside London. It is a long-stay unit that offers multidisciplinary assessment and treatment for people with mild to moderate intellectual disability and severe or chronic mental illness that prevents them from living in the community. Frequent reasons for admission are serious aggression, sexually challenging behaviour, and fire-setting, and most people admitted have had contact with the law prior to admission. A new building was

recently constructed for this program. It is a freestanding contemporary facility that allows for private and double rooms, multiple common areas, an inner courtyard, and a fenced outer recreational area. Treatment is based on the principles of sequential single hypothesis testing and functional analysis. Therapeutic interventions may include behavioural, pharmacological, psychological, and/or social interventions. The goal of admission is to return the person to the community. During the stay, the team works extensively with the community network to prepare for discharge and find the most appropriate community home that will help the individual succeed (Xenitidis, Russell, & Ward, et al., 1999).

Neuropsychiatric Disabilities Unit, Worcester, Massachusetts, USA

This 10-bed unit is an acute adult psychiatric facility housed in a major medical center. People must meet emergency psychiatric admission standards and pose a danger to themselves or others, including medical and self-care risk. The length of stay is ideally 10 days to two weeks, because of health care insurance company policies in the United States. Individuals may be referred by a case manager from the state Department of Mental Retardation, through service agreements with the START program (previously discussed in the Secondary Mental Health Care section above), or from private practitioners, emergency rooms, and families. Periodically, people are admitted for adjustment of psychoactive medications because they can only be managed safely within a 24-hour supervised medical setting. The core treatment team includes a psychologist/program director, a Master's level clinical nurse specialist, a medical director who is also the attending psychiatrist, a primary care physician consultant, a behavioural specialist, a clinical social worker, and an occupational therapist. People who present with significant medical needs, suicidal risk, or who are at risk for assaulting other patients may be assigned 1:1 staff (a mental health counsellor who will monitor and assist the individual, remaining within close proximity at all times.) The unit has a structured day program, mainly in the form of group sessions that occur from early morning until evening. Everyone is expected to participate in the sessions unless they are not able to do so (Charlot, Abend, Silka, et al., 2003).

An important goal for the unit is to provide holistic treatment. Most clients have required multimodal treatment with a combination of pharmacotherapy, medical treatments, behaviour modification, milieu therapy, family support, and systems interventions. Discharge planning begins the day of admission and participation of the community support network is required.

CHAPTER 4: Core Information and Research on Developmental Disabilities

Causes of Developmental Disabilities

A developmental disability can be caused by any condition that impairs development of the brain before birth, during birth, or in childhood and adolescence. With this wide range of causal pathways, individuals with a developmental disability make up a very heterogeneous population. In spite of advances in research, for about 50 percent of individuals the cause of the disability cannot currently be determined.

Among known causes of developmental disabilities, substance use, and poly-substance use during pregnancy is a growing and serious problem. Substances include alcohol, tobacco, and illegal and prescription drugs. Alcohol and other drugs can cause a wide range of birth defects as well as cognitive and other developmental disabilities (Streissguth & Kanter, 1997); however, the effects on learning and behaviour may not be evident until school entry. Unfortunately, the most common form of substance use today is poly-substance use, whereby the developing fetus is exposed to a combination of alcohol, tobacco and illegal drugs, increasing the risk of damage. See pages 24 and 107 for more on this.

Early identification, assessment, diagnosis, treatment, and ongoing appropriate care of mental health disorders are important both for remediation of these conditions and in order to prevent the occurrence of secondary disabilities. For example, in fetal alcohol exposure (see page 109 for more information about Fetal Alcohol Spectrum Disorder.), the permanent neurodevelopmental deficits (brain damage), growth impairment, and other birth defects are considered the primary (permanent) disability, while secondary disabilities include poor coping skills, high rates of substance use, and mental health disorders such as suicide, depression, anxiety and Attention-Deficit Hyperactivity Disorder. All of these disabilities can be mediated by proper interventions and support. Timely and appropriate intervention can have a significant impact on outcomes from childhood into adulthood for individuals with a developmental disability, regardless of the cause.

Genetic or Inherited Factors

There are many examples of inherited genetic conditions that may be associated with developmental disability. For example, tuberous sclerosis complex and neurofibromatosis are the result of an error in a single gene. Fragile X involves too many repeats of one gene sequence on the X chromosome, and the number of repeats of this gene increases over several generations, finally resulting in a male child with the full Fragile X syndrome. Prader-Willi Syndrome is sometimes linked to a deletion of a gene on chromosome 15, but not necessarily (Hagerman & Hagerman, 2002). Down Syndrome—the most frequent chromosomal cause of developmental disability—involves an error in the replication of chromosome 21, and as a result there is too much genetic material produced. As stated previously, new technology has allowed examination of an individual's genes, and many new conditions are being identified, as well as many isolated genetic problems that might account for the specific cause of an individual's disability. (See page 108 for more detailed information.)

Premature Birth

Prematurity is defined as birth occurring before 36 weeks gestation. With significant advances in perinatal care, more premature babies are surviving than ever before. Most of these children do very well and have minimal disabilities; however, some have very special needs in terms of learning problems, physical disabilities, sensory deficits, and attention deficit. For this reason, many graduates of neonatal intensive care units require follow-up and long-term care.

External Influences on Brain Development

There is now accumulating evidence that stress during pregnancy, as well as maternal and early infant nutrition, can affect the development of the fetal and infant brain. Research suggests that stress during pregnancy can affect the intrauterine hormonal environment, which may then place the infant at later risk of depression. Further, a stressful intrauterine environment can affect nerve connections in the brain and the architecture of brain development. The effects of early malnutrition on learning and cognition are well known.

Environmental Factors after Birth

Multiple factors can influence a child's development. These include malnutrition; exposure to toxins (e.g. lead from paint or from motor vehicle exhaust); breast milk containing concentrations of environmental toxins such as dioxins and polychlorinated biphenyls (PCBs); alcohol, crystal methamphetamine, or marijuana use while breast feeding; emotional deprivation; and the effect of multigenerational disability and poverty. Gasoline sniffing and early use of drugs

and alcohol by children and youth can affect cognitive and social development and potentially lead to life-long addiction. (pages 29-31)

Childhood Injury or Disease

Numerous infections, medical conditions, and accidents can cause a developmental disability. For example, bacterial meningitis, head injuries, and brain tumours can cause significant impairment in cognitive development.

DSM-IV-TR Classification System

The diagnosis of MR in the DSM-IV classification system is coded on AXIS II, and identifies four ascending levels of intellectual impairment, as seen in the chart below.

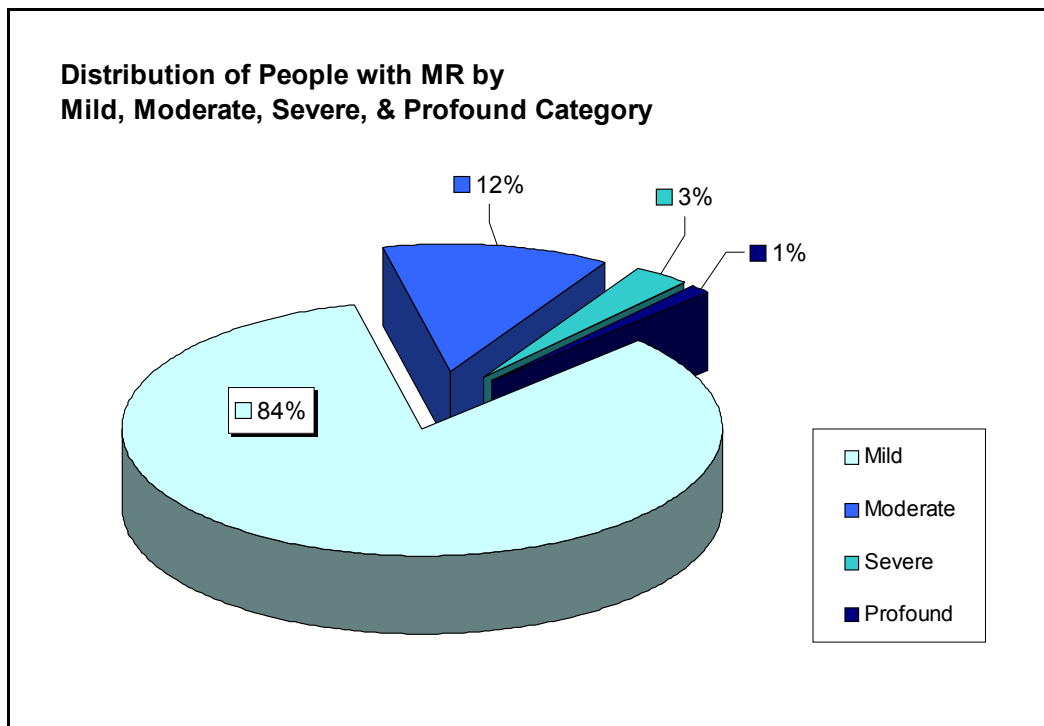


Figure 4: Distribution of people with MR by mild, moderate, severe, and profound categories of IQ scores.

Mild MR

Approximately 80 to 85 percent of people with MR have a mild impairment, classified by DSM-IV-TR as an IQ level ranging from approximately 50 to 69. Mild MR refers to those with minimal impairment of daily living skills, academic

Borderline Intellectual Functioning

This term refers to IQ levels that range from 70 to 79. People with this level of IQ are often at a great disadvantage within the entire social support system. Borderline IQ level makes a person ineligible for developmental disability services in some jurisdictions, and yet he or she may lack the cognitive ability to learn, develop, or retain the adaptive skills necessary for success in daily living. Many individuals with Fetal Alcohol Spectrum Disorder (FASD), childhood brain tumour or head injury, Asperger's Syndrome, high functioning Autism, severe learning disability, traumatic brain injury, or Tourette's Disorder have borderline intelligence but functionally are severely impaired and may "fall through the cracks" of the system of care. Many jurisdictions in the United States accept these individuals as eligible for developmental disability services by using an extensive appeal process and by making individual exceptions.

achievement levels ranging from Grade 2 to Grade 4 in basic subjects, and the ability to achieve social and vocational skills sufficient for minimum self-support, but who may, however, need guidance and/or assistance when under unusual social or economic stress.

Moderate MR

Approximately 10 to 12 percent of people with MR have a moderate impairment, with IQ levels ranging from approximately 35 to 49. Moderate MR refers to those who typically reach the kindergarten to first grade level in academic subjects, who can attend to their own personal care with moderate supervision, and who may learn to travel independently to close, safe, and familiar places. As adolescents, they have difficulties in understanding and appropriately responding to social cues and stimuli, causing social isolation and a limited or nonexistent peer network. As adults, they are usually able to perform unskilled or semi-skilled work under supervision.

Severe and Profound MR

Approximately three to four percent of people with MR have a severe impairment and one to two percent have a profound impairment. IQ levels in these populations range from roughly 20 to 34 for severe impairment, and are under 20 for the profoundly impaired. These individuals have significant limitations in their verbal communication skills and may benefit from communication aids and/or non-verbal communication supports (e.g., gestures or sign language, books and boards with words or pictures that the person points to, computerized units that can speak whatever the person types, etc.). They may also have one or more sensory and/or motor impairments, and they typically need assistance with most aspects of personal care. When in the community, they need close supervision, but they may be able to perform simple tasks with direct supervision. They need support and advocacy to gain access to appropriate and timely health care.

Intelligence Tests and Their Limitations

Intelligence tests do not conform to the actual documented epidemiology of MR. This is because the tests are artificially designed to conform to the statistical normal curve, with a mean of 100 and a standard deviation of 15. Further, the cut-off for MR has changed over time. Alfred Binet, who developed the first IQ test with Theodore Simon in 1905, first identified MR as an entity. He did this for the purpose of selecting those Paris school children that needed special help in small classes, and he defined the three major categories of delay roughly corresponding to mild, moderate and severe-profound.

By the mid 20th century, the diagnosis of ‘mental deficiency’ included performance of only one standard deviation below the mean (equivalent to an IQ of 85). This was used by many school systems as the criteria for access to special education. In 1959, the official manual of the American Association on Mental Deficiency placed the IQ cut-off at 85, officially one standard deviation below the mean. In 1973, this was changed to an IQ cut-off of 70 or below, chosen since it represents the lowest two to three percent of the population (Grossman, 1983; Heber, 1959). Because the IQ test is artificially scaled to a bell curve (statistical normal distribution), a rise in a few points quickly brings about the inclusion of many more individuals. Thus, an IQ of 85 potentially includes 16 percent of the total population. An IQ of 70 remains the present international standard. Thus, the cut-off for services is arbitrarily set, and future national and international policies may consider a more comprehensive set of criteria, including greater focus on adaptive functioning.

Using an IQ of 70 or below as the cut-off would theoretically result in two to three percent of the population being considered to have MR. Actual field studies and registries have suggested, however, that those who meet the full criteria probably constitute about one percent of the general population (Mercer, 1973a,b). This is due to the inclusion of the other criterion of delay in adaptive skills, as well as to statistical problems with test development. Furthermore, IQ does not necessarily correlate with overall functioning. For example, some individuals with an IQ of 65 can live semi-independently, read and write, and take public transportation, while others cannot. In contrast, there are some individuals with an IQ of 79 (or even higher), who have unusual brain development such that they are unable to manage basic daily independent living skills. Thus, if adaptive function were the main criterion, those individuals would potentially qualify for developmental disability services in some jurisdiction.

Assessment of Adaptive Functioning

The assessment of adaptive functioning proposed by the American Association on Mental Retardation-AAMR (2002) requires adaptive limitations in only two of 10 areas: communication, self-care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work (AAMR, 2002). The American Psychological Association did much work on this issue, pointing out the significant over-inclusion of “intellectually normal” people with a requirement of limitations in only two areas (Jacobson & Mullick, 1996).

A number of tests of adaptive behaviour have been published by psychological testing companies. These include the *Adaptive Behavior Scale-Residential and Community, Second Edition* (Nihira, Leland & Lambert, 1992), *Scales of Independent Behavior-Revised (SIB-R)* (Bruininks, Woodcock, Weatherman et al.,

1996), and the *Vineland Adaptive Behavior Scales* (Sparrow, S.S., Balla, D.A. & Cicchetti, D. V., 1984).

A new test, published in 2004, the *Supports Intensity Scale (SIS)* (Thompson et al., 2004), focuses on the adaptive needs enabling people to live successfully in the community rather than focusing on their adaptive deficits. The *SIS* may be a helpful adjunct to the *SIB-R* or *Vineland* tests of adaptive function. All tests have their individual advantages and disadvantages for assessing any particular individual. In addition, they all rely on a third-party informant familiar with the person to give the information for rating the individual's adaptive functioning levels. Thus, the third party ideally needs to be well acquainted with the person's adaptive functioning in order to communicate this appropriately during the assessment. For further information, see the list of assessment resources in *Appendix A* on page 123.

Epidemiology and Prevalence of Developmental Disabilities

Research on the epidemiology of developmental disability and mental health disorders has found wide variation in prevalence rates depending on the size of the sample, location of the study, and method used to identify a co-occurring mental illness. Nonetheless, in well-designed research studies, estimated rates of mental illness and challenging behaviours are always found to be significantly higher than in the general population. There is a need for further ongoing evidence-based research within this population.

The peak prevalence of developmental disability is said to be three percent of all children at age 12. However, since many of those with mild intellectual impairment can adapt successfully in to adulthood, one percent of the population is usually quoted as an estimated prevalence rate. Of this one percent, estimates of those receiving community living services range from 30 percent to 89 percent in different jurisdictions. There are many individuals in the community who are not part of the service system, the majority of whom do well when supported by family, friends, and their family physician or paediatrician when younger.

BC Findings

In British Columbia, the 2006 estimate for general population age six and older is 4,038,500 (<http://www.bcstats.gov.bc.ca/DATA/POP/pop/Project/p30notes.PDF>). One percent of this population will have MR (Mercer, 1973 a,b). Of this one percent, at least 39 percent of children age six to 18—or 2,558 children and youth—and 30 percent of adults—or 10,148 adults—require mental health services (Emerson, 2003; Hudson C., Chan J., 2002; Smiley, 2005). Thus, the total number of children age six and over, youth, and adults having MR and

requiring specialized mental health and addiction services in BC is estimated to be 12,706 individuals.

Canadian Findings

Comprehensive studies of prevalence support the one percent prevalence estimate mentioned above (Mercer, 1973a,b). Of this one percent, individuals receiving services, or known to the service system range from 30 to 70 percent in different jurisdictions. This is known as administrative prevalence. National and international reviews of administrative prevalence suggest that Canadian rates should be between 0.80 and 0.90 percent of the population (Ouellette-Kuntz, 2001).

Results of prevalence studies in Ontario range from 0.56 percent (Nuyen, 1996) to 0.70 percent of the population (Ontario, MCSS, 1999; Brown, Raphael, Renwick, 1997). An analysis of a cross-system survey conducted in one county in Ontario found an administrative prevalence rate between 0.80 percent and 0.90 percent for developmental disability (Nuyen, 1996). Estimated prevalence rates and those actually receiving services do not vary significantly for individuals with more severe disabilities, which is stable at three to four per 1,000, or 0.3 to 0.4 percent (Roeleveld, Zielhuis, & Gabreels, 1997, pages 25-26).

International Findings

In a meta-analysis of all studies at that time (1990), Reiss found rates of mental health problems of 15 to 50 percent in adults with developmental disabilities (Reiss, 1994). He noted that low prevalence rates were generally found in surveys that relied on retrospective review of case files, while higher rates were found in surveys using professional interviewers and more elaborate scientific methods. Reiss conducted a case-file retrospective review, finding a prevalence of 10 percent for mental health disorders in children with developmental delay among 5,637 public school case files in Illinois in the United States (Reiss, 1990).

The Isle of Wight study remains the most scientific of epidemiology studies of this client population. Rutter and his colleagues found that 50 percent of children with neurological and developmental disabilities, ages nine to 11, had behavioural disorders. This research project incorporated the examination of a normative population, rating scales completed by parents and teachers, and an individual diagnostic interview, providing the most rigorous methods (Rutter, Tizard, Uule, Graham, & Whitmore, 1976). For children with developmental disabilities, parents' interviews found ratings of 30 percent to have a behavioural disorder compared to teachers' ratings of 42 percent, and psychiatric interviews found 50 percent compared to a finding of seven percent in the general

Note

The term *challenging behaviours* has been used in the literature when referencing this population, often without distinguishing between causes related to psychiatric conditions and/or those related to other psychological, emotional, environmental, or physical factors. This is similar to other areas of research where there is a progression to greater specificity. Individuals with a developmental disability require a comprehensive, integrated biopsychosocial approach to assessment and care. Therefore, mental health services for this population require integration of behavioural assessment and treatment in addition to psychiatric and medical assessment (Baker and Blumberg, 2006, pages 40-43).

population. This landmark study concluded that children with neurological impairments and developmental disabilities were at significant risk for behavioural and mental health problems.

Gillberg, Persson, Grufman, & Themner (1986) followed 149 youngsters in a four-year birth cohort at ages 13 to 17 and found a 57 percent rate of behavioural disorder among those with mild MR and 64 percent among those with severe MR. Gath & Gumley (1986) studied 346 children with Down Syndrome in a health care region in England and found 38 percent with behavioural disorder; a matched group of children with disabilities but without Down Syndrome resulted in a rate of 49 percent having a behavioural disorder.

McQueen, Spence, Garner, Pereira, & Winsor studied 221 children with intelligence quotients below 55, in a four-year birth cohort, in the maritime provinces of Canada (1987). These researchers found that 32 percent had behavioural disorders and nine percent were identified as having a psychiatric disorder.

Emerson investigated 10,438 children between five and 15 who had participated in a large epidemiological survey of mental health in children in the United Kingdom. He conducted a secondary analysis and identified 2.6 percent as having developmental delay. For those with delay, the prevalence of psychiatric disorders was greater compared to their typical peers (39.0 percent and 8.1 percent respectively). The prevalence of conduct disorder, anxiety disorders, Attention-Deficit Hyperactivity Disorder, and pervasive developmental disorder was increased (Emerson, 2003). Deb and colleagues found similar results in adults with developmental disabilities. Their study found psychiatric disorder rates of 14 to 22 percent, with an increased rate of psychosis and phobias. In this study, however, Autistic disorder, Attention-Deficit Hyperactivity Disorder, and personality disorders were not included (Deb, Thomas, & Bright, 2001).

Other studies have found puzzling results. For example, Rojahn, Borthwick-Duffy, & Jacobson (1993), reported a prevalence study of psychiatric and behaviour disorders among all individuals with MR registered from California (89,419) and New York (45,683 individuals). This study analyzed information in a database of behavioural surveys and recorded psychiatric diagnoses made by qualified professionals. In the New York sample, only 21 individuals with developmental disabilities were diagnosed with affective disorders, and in California, only 599. This large-scale study relied on extensive databases completed by a variety of state workers reporting mental health disorders on a third-hand basis. It is not possible that, for example, only 21 people with developmental disabilities in New York had mood disorders; this also underscores the problems in identifying the existence of mental illness in the developmental disability population when working from a government database. Borthwick-Duffy (1994) reported a serious problem in reporting the true level of

psychiatric illness among people with developmental disabilities, and the lack of diagnosis and treatment (pages 43-44).

Challenges Facing Persons with Developmental Disabilities

Medical Problems

Individuals with developmental disability have more medical problems such as seizure disorders and gastrointestinal problems. Rates of morbidity are often substantially higher than those of the general population, especially in people with severe and profound disabilities, and many common medical conditions that are treatable or preventable may go undiagnosed (Beange, McElduff & Baker, 1995). There is a higher rate of motor or sensory impairments, and many individuals have visual, hearing, or physical impairments as well. Genetic disorders cause a range of impairments, and tend to occur more frequently with severe and profound developmental disability and there may be higher associated mortality rates. Prevention and early intervention carries on beyond childhood, and applies to both physical and mental health.

Communication

People with developmental disabilities vary greatly in their ability to understand and communicate their needs, discomforts, and concerns. As a result, physicians and other health care professionals must adapt interview styles in order to accommodate individual communication needs, and also consider and seek out reports from family members, teachers, third-party caregivers, and associated support staff. Collateral information, however, should not be considered a substitute for direct assessment with the individual.

Informed Consent

Much of the medical system and all of the legal system is based on the premise that people are mentally capable and able to understand what is told to them, and therefore are capable of making reasoned decisions for themselves. People with developmental disabilities have a range of abilities and disabilities, which may make it difficult for them to make valid decisions at times. Consent is a cornerstone of modern health care, but the route to obtaining **valid** consent from a person with a developmental disability can be complex and challenging. It is required that informed and valid consent is obtained prior to providing health care and support services for people with developmental disabilities, and *substitute decision makers* may be needed for many individuals, some or all of the time.

EU Develops Health Indicators

A European Union sponsored project on Health Indicators (Pomona, 2004) for people with developmental disabilities has identified 18 key indicators, which include both health and mental health domains with the focus on the individual. The *Canadian Institute for Health Information (CIHI)* has developed a list of quality indicators that will help to monitor key areas in the provision of mental health services for this client population. (The CIHI framework is detailed on page 53).

Behavioural Phenotypes

Some developmental syndromes are associated with behavioural patterns and psychiatric disorders. When a strong correlation occurs and is reliably identified in a diagnosed, specific syndrome, it is termed a *behavioural phenotype*. The importance of identifying the phenotype is that the patterns of behaviour are biologically linked to the syndrome and are not learned. Identifying the syndrome helps professionals to be aware of an individual's higher risk of associated medical conditions and employ preventive approaches. At the same time caution must be exercised as individual differences abound and the phenotype is simply one piece of information, which helps to provide a more complete understanding of the individual. See page 110 for more on this topic.

The duties of a Substitute decision maker (SDM) are to give or refuse consent on the basis of the adult's known beliefs and values, or in the adult's best interests if his or her beliefs and values are not known. Prior to the decision, the SDM is to consult with the adult to the greatest extent possible, in order to try to determine what the adult's wishes would be. In British Columbia, there are four laws that address issues of consent and protection for persons aged 19 years and above. Two of the four laws address issues of consent for adults directly: The *Representation Agreement Act*, and the *Health Care (Consent) and Care Facility (Admission) Act*. However, only the Health Care Consent section is currently in force (<http://www.trustee.bc.ca>). Children and youth in BC are under the protection of the *INFANTS ACT (1996)*, which establishes guidelines for health care providers as to when children and youth may give consent for their own health care (see http://www.qp.gov.bc.ca/statreg/stat/I/96223_01.htm for details).

Persons with developmental disabilities may be at risk of being offered a different (often lower) standard of care than that accorded the general population. Health care providers need to be aware of personal and societal biases and engage in non-discriminatory practices, offering, as a minimum, the accepted general standard of care to all persons under their care. For more on this, see page 22.

Substance Abuse

Some people with developmental disability do use addictive substances, though the rate appears to be relatively low among this client population compared to the general population. Appropriate and accessible addiction treatment services are essential for those with substance use disorders. Furthermore, treatment often requires accommodating the special learning needs of this population, through strategies such as shorter sessions, use of plain language, visual as well as written materials, and support from a community living worker to act as an 'interpreter' in the sessions (if not geared to people with developmental disabilities) and to assist in the learning of treatment concepts. For more on this, see page 105.

Sexuality

Another frequent reason for referral is confusion or problems around sexuality. This is an area where people with developmental disability often face challenges. The potential for healthy sexuality in many people with a developmental disability is limited by several interrelated factors, including poor control over their environment, lack of privacy, limited opportunity to develop healthy sexual relationships, and lack of appropriate teaching about consent and boundaries.

Encounters with the Legal System

As with any other citizen, a person with a developmental disability may become a victim of a criminal act or witness or commit a crime. The response of the justice system and the community will vary depending on the degree of knowledge about developmental disability in general and—where relevant—depending on awareness of the need to accommodate specific aspects of the person’s disability. For more on this, see page 97.

Psychiatric and Behavioural Intervention

Aggression towards self or others is the most frequent event that initiates a psychiatric evaluation for people with a developmental disability. In the past, the aggression or problem behaviour was seen as a focus for treatment. There is no specific aggression-diagnostic relationship and aggression may be a symptom of any psychiatric disorder or a psychosocial issue. Due to the frequent occurrence of aggression and self-injury in individuals with developmental disability, there has been a historical trend for overuse and misuse of antipsychotic medications. These medications are often prescribed for ‘behaviour’ without understanding the context, meaning, and underlying cause of the behaviour. Similarly, there has been a tendency to segregate interventions as either “behavioural” or “psychiatric.” The best approach to diagnosis is an integrated approach that combines understanding of the behaviour in the context of the mental health symptoms and visa versa.

Legislative Requirements of Health Care Providers

The delivery of health care services to vulnerable persons is governed by four pieces of legislation in British Columbia. Health care providers in BC should be familiar with the following four Acts:

The Health Care (Consent) and Care Facility (Admissions) Act

Section 6 of this Act describes the elements of consent. According to the Health Care (Consent) and Care Facility (Admission) Act, every adult who is deemed not capable of giving valid consent, needs to have a *substitute decision maker* (SDM). The consent process for minor vs. major health care is different. In the legislation, **minor health care** is anything not specifically listed as major. Treatment with medications, for example, fits into minor health care. Emergency procedures are not held to this slower process, and there are procedures that **cannot be consented to by a substitute decision maker**: psychosurgery, experimental health care, organ or living tissue donation, aversive stimuli for behavioural change, and non-therapeutic sterilization. (<http://www.trustee.bc.ca>)

Is it behaviour or is it mental illness?

“Understanding that these behaviours serve a function for the individual, no matter how difficult it is to understand, provides a method for linking services for individuals utilizing the best of both psychiatric and behavioural intervention. Combining information related to psychiatric symptoms into a behavioural model also eliminates the frequently asked dichotomous question, ‘Is it behaviour or is it mental illness?’ The most accurate answer to this question is often ‘both’ and without an understanding of how the two interact, a real understanding of the question is impossible.” (Baker & Blumberg, 2006).

Safeguards

Policies and procedures must be in place to ensure that any use of behavioural strategies and safeguards conforms to safe, ethical, and accountable practice standards and makes use of evidenced-based best practice intervention strategies. Written guidelines and protocols that are reviewed regularly will help to ensure consistency in approach among caregivers and increased personal safety for this client population.

The Representation Agreement Act

This legislation states that its purpose is “to provide a mechanism...

- a. to allow adults (age 19 and above) to arrange in advance how, when, and by whom decisions about their health care, personal care, financial affairs, or about other matters will be made if they become incapable of making decisions independently, and
- b. to avoid the need for the court to appoint someone to help adults make decisions, or someone to make decisions for adults, when they are incapable of making decisions independently. If a person signs a Representation Agreement under Section 7, there is no legal test of incapability required and no lawyer is needed, whereas a test of incapability and a lawyer are required for a Representation Agreement under Section 9.” (<http://www.trustee.bc.ca>)

The Adult Guardianship Act

The purpose of this legislation is to offer protection to vulnerable persons from abuse which is defined as “emotional, physical or mental harm” and also protection from “self-neglect”. The Guiding Principles of this Act state that “all adults are entitled to live in the manner they wish and to accept or refuse support, assistance or protection as long as they do not harm others and they are capable of making decisions about those matters”. Capability in this Act, as in all of the other Acts is presumed “until the contrary is demonstrated”.

(<http://www.trustee.bc.ca>)

The Infants Act (1996)

The term “Infants” in this legislation refers to anyone under the age of 19 years. In Part 2-Medical Treatment, Section 17 states: “ 17 (2) Subject to subsection (3), an infant may consent to health care whether or not that health care would, in the absence of consent, constitute a trespass to the infant’s person, and if an infant provides that consent, the consent is effective and it is not necessary to obtain a consent to the health care from the infant’s parent or guardian.”

(http://www.qp.gov.bc.ca/statreg/stat/I/96223_01.htm)

CHAPTER 5: Psychiatric and Other Medical Disorders Co-occurring with Developmental Disability

Diagnostic Issues, Research, Case Studies, and Treatment Planning

Issues in Diagnostic Classification

The primary manuals used for psychiatric classification (DSM – IVR and ICD-10) were developed for the general population and have inherent limitations in application to people with developmental disabilities. In response, the Royal College of Psychiatrists in the UK and the Republic of Ireland, have developed the *DC-LD Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities* (2001). The DC/LD¹⁹ has been developed to accommodate unique diagnostic issues, such as behavioural phenotypes²⁰, which present in developmental disability populations, and to put other mental health disorders into a hierarchical framework that can facilitate both good practice and further research.

The Challenge of Proper Diagnosis

Most mental health professionals are not trained in developmental disability or *developmental mental health*. Unlike individuals in the general population, the vast majority of people with developmental disabilities cannot verbalize their symptoms and history adequately for the traditional psychiatric evaluation. (Sovner, 1986; Sovner & Hurley, 1983). Further, their psychiatric presentation may in fact be atypical or different than expected. For example, if a person with a

“Developmental disability compounds these disparities because many health care providers avoid clients with this condition. Without direct clinical experience, health care providers may feel incapable of providing adequate care. They may not value people with developmental disabilities and their potential contributions to their own health and to their communities.” (*Closing the Gap*, 2002).

¹⁹ LD stands for Learning Disability, the UK equivalent to Developmental Disability, and DC stands for Diagnostic Criteria.

²⁰ A behavioural phenotype is a pattern of behaviour that is reliably identified in groups of children and adults with known genetic or other syndromes and is not learned. See section on behavioural phenotypes for further explanation.

Importance of understanding the meaning of challenging behaviour

“Understanding that these behaviours serve a function for the individual, no matter how difficult it is to understand, provides a method for linking services for individuals utilizing the best of both psychiatric and behavioural intervention. Combining information related to psychiatric symptoms into a behavioural model also eliminates the frequently asked dichotomous question, ‘Is it behaviour or is it mental illness?’ The most accurate answer to this question is often ‘both’ and without an understanding of how the two interact, a real understanding of the question is impossible.” (Baker & Blumberg, 2006).

developmental disability develops a major depressive episode, he or she may verbalize somatic complaints or become aggressive, rather than articulate an experience of mood state or frustration with coping with problems in life.

Psychiatric clinicians may also ignore the signs of mental illness due to the presence of a significant developmental disability. Reiss and his colleagues postulate that psychiatric clinicians are often so overwhelmed, or distracted by the developmental disability, that many individuals with clear psychiatric disturbance are judged to have no mental health symptoms, a situation termed *diagnostic overshadowing*. Further, clinicians may then be so influenced by regressive or aggressive behaviour, that they see only the “behaviour problem” (termed *behavioural overshadowing*) and assume that the behaviour is “learned” and that the client will respond only to behavioural interventions.

The best approach to diagnosis is an integrated approach that combines understanding of the behaviour in the context of the mental health symptoms and visa versa. A *functional assessment* (of problem behaviour) is defined as a set of processes that gather information about an individual’s behaviour and the variables that predict and maintain the occurrence of that behaviour (Horner, 1994).

CASE EXAMPLE 3

Misunderstanding the function of behaviour

A young woman with mild developmental disability has been increasingly withdrawn. She lives in a small group home and spends most of the day in her room. She is in danger of losing her job due to frequent absences. In the morning, the group home staff wake her and prompt her to get ready for work. She refuses and uses some profanities. A little time passes and, concerned that she will be late again, a preferred staff member repeats the prompts to be up and get ready. The young woman screams at her and hits the staff member. The staff member retreats, frustrated and angry, after the assault. The staff feel the client is being resistive and aggressive. They meet and plan behavioural interventions using a mixture of incentives (access to preferred activities) and punishments (loss of preferred activities) to get her to go to work and be more involved in social activities. The intervention is unsuccessful.

The young woman becomes increasingly withdrawn and aggressive. She refuses food and is eventually hospitalized. This young woman had an undiagnosed depressive illness, and her depressive symptoms reduced the reinforcing value of work (pay check) and social activities (interaction). The prompts to go to work or engage in activities are perceived as aversive, which triggers refusals and aggression. Lack of understanding of the relationship between depressive symptoms and the young woman's behaviour made the intervention fail and the situation worse (from Baker & Blumberg, 2006).

Frequency of Psychiatric Disorders

There is consensus in the literature that people with developmental disabilities experience a significant rate of mental health disorders based on estimated prevalence rates. At least 39 percent of children and youth, and at least 30 percent of adults with a developmental disability will require specialized mental health services. (Emerson, 2003; Hudson C, Chan J, 2002; Smiley, 2006). See page 74 for more information about prevalence and epidemiology.

Causes for the High Rate of Mental Health Problems

There are multiple reasons for the significantly high rate of mental health issues in the developmental disability population. First, due to developmental disabilities, these individuals may have diminished verbal and communication abilities. Thus, they may not be able to use language adequately for coping skills.

They may not be able to analyze situations, develop coping statements and strategies, or use language to control or moderate their behaviour sufficiently. For example, if criticized by a supervisor, the individual may take the critique literally and could be highly impacted, resulting in emotional devastation or anger. He or she might also be unable to develop multiple interpretations of the event – e.g. “She is having a bad day,” or “She criticizes everyone,” or “I will make changes in my work style, but I still do a good job.”

Social rejection is another continual stressor for people with developmental disabilities. They experience rejection in the community frequently, and are well aware that it has something to do with their disability. Attempts to develop relationships with non-disabled people are frequently rejected, and often quite rudely. Social rejection becomes a major issue at many life-developmental stages (Levitas & Gilson, 2001), and evidence directly links life stresses with psychiatric disorders in this population (Hastings, Hatton, Taylor, et al., 2004). Furthermore, Lunskey and her colleagues linked level of social support to stress and psychiatric problems (Lunskey & Benson, 2001; Lunskey & Haverkamp, 1999).

Higher rates of physical, emotional, and sexual abuse may also be responsible for the higher rate of mental illness. Sobsey, Sharmaine, Well, et al. (1992) developed an annotated bibliography documenting research on the extent of abuse of people with disabilities. As a result, Posttraumatic Stress Disorder, depression, and anxiety disorders may occur frequently but are often unrecognized and under-treated.

Lastly, the incidence of mental illness is also related to the neuro-cognitive functioning of the brain itself. Deficiencies in neurotransmitter systems and biologically based over-arousal also contribute to mental health issues and/or challenging behaviours in this population.

Awareness of Impact of Health Problems on Mental Status

People with developmental disabilities have a higher incidence of physical problems including epilepsy, hearing loss, visual problems, constipation, musculo-skeletal problems, dental needs, and hypothyroidism. Some persons with specific syndromes such as Down Syndrome have a wide range of potential physical problems (Van Allen, Fund & Jurenka, 1999). Often, health problems are not diagnosed and behaviour resulting from undetected health issues are attributed to the person’s developmental disability (Kastner, Walsh & Fraser, 2001). Lunskey and her colleagues (Lunskey, Emery & Benson, 2002) found deficiencies in reports of health behaviours, physical complaints, and medication facts.

An important study by Beange and his colleagues (1995) in Australia found that persons with a developmental disability had an average of 5.4 medical disorders, half of which had not been detected prior to the survey. 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.

Epilepsy is more common in people with any developmental disability. It occurs in two percent of the general population, and in 25 to 35 percent of people with neurologically based disabilities as it is a manifestation of brain injury or differences in brain development. Seizures may be provoked by acute events including infection, head injury, chemical imbalance, stroke, or brain tumours. Active seizures affect the mental status of the person. In addition, psychiatric symptoms may be directly or indirectly related to the seizure disorder. If a person has epilepsy and a psychiatric disorder, control of the epilepsy is the primary goal (Benjamin, 2000; Barnhill & Hurley, 2003).

CASE EXAMPLE 4

Effect of under-treated/undiagnosed physical illness on mental health

A young woman in her mid-thirties with Down Syndrome and a moderate developmental disability has been living independently with support services in her own apartment for several years. A referral was made to a community psychiatrist familiar with developmental disabilities for re-assessment of depression, possible early onset dementia, suicidal thinking, and failure to respond to treatment with a Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant.

This young woman had gained considerable weight and gave a history of sleeping on four pillows, fatigue, and having many symptoms of depression. Recommendations included overnight fingertip oximetry to check for sleep apnea (test was positive for significant sleep apnea); a re-check of thyroid function (was on a low dose of thyroid replacement hormone); and fasting blood sugar for diabetes (normal). Her thyroid function was abnormal. It indicated that her dose of thyroid replacement was too low and it was subsequently increased.

A new family doctor was found who was willing to support the recommendations and work with the community team. Treatment for sleep apnea was initiated with a continuous positive airway pressure (CPAP) machine. However, checks for compliance showed that the machine was used sporadically. The social worker and care team suggested that the young woman consider a change in living situation and move in with an experienced caregiver. The family supported this move. This new living situation with increased support has been positive and use of the CPAP has been consistent, with resulting increase in energy and improvement in thinking and in mood. Weight loss has been possible with persistent effort and pride by this young woman.

Psychiatric Assessment Issues

Conducting the Psychiatric Interview / Mental Status Examination

The psychiatric interview is a verbal exchange between the interviewer and the patient. When interviewing a person with a developmental disability—even if the disability is mild—physicians/clinicians cannot usually conduct an interview successfully using routine guidelines.

Involve Support Persons

People with developmental disabilities vary greatly in their ability to understand and communicate their needs, discomforts, and concerns. As a result, the physician/clinician must rely on the reports of family, third-party caregivers, or associated support staff, in addition to interviewing the person with the disability. It is helpful to speak with a family member or support person/caregiver prior to interviewing the person, along with reviewing previous documents. The support person may be able to describe the individual's level of functioning, communication strengths, and interests. The caregiver can often make suggestions about how best to engage the person and what to avoid—sitting too close, for example, or asking too many questions. As well, the person to be interviewed may feel more comfortable if a support person is present for part of the interview.

Use Communication Aids Where Appropriate

A variety of communication aids exists and many people in this population are able to use them successfully. Some use gestures or sign language, books or boards with words or pictures that the person points to, or computerized units which can speak whatever the person types.

Moderate Interview Language Appropriately

The language of the interview must be significantly altered when communicating with individuals who have a developmental disability. The physician/clinician must use plain language and short sentences, speak slowly, and avoid using leading questions. Starting with non-threatening questions about interests and favourite activities will help to decrease potential anxiety and also allow the interviewer to “meet” the person. Between questions and statements, the person must be given time to process the information. (Levitas, Hurley & Pary, 2001).

There is also a potential problem of acquiescence to the interviewer by people with developmental disabilities (Matikka & Vesala, 1997). The person with a developmental disability may want to please the examiner, and may think of the

exchange as a test in school. He or she may be anxious to produce the “right answer” to questions such as “Do you hear voices of people not there?” or be anxious to deny problems with anger or aggression due to a fear of “getting into trouble.” Lack of contextual understanding of the psychiatric process usually results in unreliable and inadequate answers to most of the typical questions of the psychiatric interview.

Influence of Developmental Disability on Diagnosis

There are four major ways that having a developmental disability may influence the diagnosis of a mental disorder (Sovner, 1986):

- intellectual distortion
- psychosocial masking
- cognitive disintegration
- baseline exaggeration

Intellectual Distortion

Individuals with developmental disabilities usually have significant limitations in their ability to think abstractly and communicate verbally. Thus, answers may be “distorted” in a similar way to how a child might answer, i.e. answers may be more concrete/black and white.

Psychosocial Masking

Psychiatric symptoms will occur within the developmental context. For example, in the grandiosity of a manic episode, people with a developmental disability may believe that they can drive a car or spend all their earnings from a part-time job, instead of saving in the usual way for a CD or an outing. Suicidal intent may be expressed through attempts to choke oneself with one’s hands. This would not result in death; however, it signifies that this individual believes that he or she could die that way and so the intent should be taken very seriously.

Cognitive Disintegration

Due to lack of cognitive reserve, many individuals with developmental disability become significantly regressed and lose their ability to function when under stress or during a psychiatric episode. For example, in a major depressive episode, a person may take to bed, become mute, and refuse to eat, wash, or go to the toilet. This degree of regression is very rare among patients in the general population.

Baseline Exaggeration

During stress or an acute psychiatric episode, pre-existing challenging behaviours that occur at a low base rate level may become more frequent and more intense. The challenging behaviours then become the focus of the caregivers and the focus of a psychiatric consultation. As a result, observation of other symptoms and appreciation of more psychological factors at work is diminished, while everyone focuses on the “behaviour.”

Managing Challenging Behaviour

Aggression and Self-Injurious Behaviour

Aggression is the most frequent symptom that initiates a psychiatric evaluation for people with a developmental disability.

Due to the developmental disability, verbal controls are less effective over behaviour, and many difficulties are “acted out.” Hurley (Hurley, Folstein, & Lam, 2003) and her colleagues found aggression the most frequent chief complaint for people with developmental disability (40 percent), compared to general population patients in an outpatient hospital setting (six percent). King and his colleagues found aggression and self-injury were among the most common reasons for referral to his psychiatric consultation service at a state developmental facility serving individuals with severe and profound developmental disabilities (King, Deantoni, McCracker, et al., 1994). Of 251 individuals referred, 30 percent were referred due to aggression; 36 percent due to self-injury; 35 percent due to medical problems; and 47 percent due to “behaviour.” Aggression and self-injury were jointly noted in 23 percent of all referrals. Charlot and her colleagues found that aggression is often a common motivating factor for evaluation. This is largely due to the fact that the caregiver—for whom aggression is a problem—initiates the referral (Charlot, Doucette, & Mezzacampa, 1993).

Edelstein and Glenwick (1997), in a study of 391 patients with developmental disabilities seeking outpatient services at a specialty clinic, found “externalizing” behaviours, such as aggression, to be the most frequent referral problem. Davidson and his colleagues in Rochester reported on their outpatient Crisis Intervention Service (Davidson et al 1994; Davidson et al 1999), finding that in their adult cohort of 278 individuals, 200 (72 percent) were referred for an aggression-related problem. In contrast, aggression is very rare among non-developmentally disabled adults. In a study examining aggressive assault among 2,916 outpatients seen by psychiatric residents in clinics of two private psychiatric hospitals, Tardiff & Koenigsberg found that three percent had actually assaulted a person, and these patients were more likely to have

childhood onset disorders, MR, or personality disorders (Tardiff & Koenigsberg, 1985).

Because, in the general population, aggression is typically seen as maladaptive behaviour due to poor social skills, the adult psychiatric community has little practical clinical experience assessing this situation. As a result, people with developmental disabilities and aggression are often misdiagnosed and possibly incorrectly treated with pharmacotherapy to suppress the symptom, or the symptom is thought to be “just a behaviour” associated with the developmental disability and not considered as a possible symptom of a mental illness.

Although aggression can be associated with depression or bipolar disorder, there is no specific aggression-diagnostic relationship. Thus, aggression may be a symptom of any psychiatric disorder, or may be due to an environmental or to a medical cause, or a combination of two or three of these factors. It should not automatically be assumed to be “due to” the developmental disability.

People with challenging behaviour (in the absence of a mental illness) are most likely to have moderate to severe learning disabilities along with the challenging behaviour. The challenging behaviour is contributed to by various circumstances, including: poor environment and lack of teaching of practical coping skills, language and speech impairment leading to frustration with communication of needs or medical problems, behaviours that may be an inappropriate learned response to past experiences or inappropriate carer responses to the behaviour (Bouras, 2003).

The occurrence of aggression may increase when the individual has multiple disabilities — physical and/or mental. Freeman and his colleagues conducted an analysis of selected findings for 3,500 individuals with Tourette’s syndrome in 22 countries. They found that not only is co-morbidity common, but also that each additional co-morbid condition progressively increases the rate of behavioural problems, such as aggression (Freeman, Fast, Burd et al., 2000). A subsequent study of the subset of the patients with Tourette’s syndrome and a developmental disability showed the same trend (Boulding and Friedlander, 2004).

CASE EXAMPLE 5

Aggression as referral reason highlighting the importance of knowing past history and meaning of specific challenging behaviour

A man, aged thirty-five, with a moderate developmental disability, was living in small group home when he was referred because of agitation, anger outbursts, and mood lability. The etiology of his disability is vague. His mother may have had Rubella during pregnancy. This individual had a past history of seizures but had been seizure free for many years. He had been institutionalized in childhood due to the family situation and his level of aggression in the home. Previous medication history included chlorpromazine, valproic acid, and carbamazepine. At the time of referral, the medication was carbamazepine with a blood level in the therapeutic range indicating that prior higher levels of medication may have been in the toxic range.

This individual has a family history of bipolar disorder, considerable family trauma, and was a victim of sexual assault during institutionalization. Early trauma and attachment difficulties were evident, in addition to ongoing trauma, resulting in difficulties with modulating emotions. However, mood symptoms were not felt to be currently present (and may have been decreased by treatment with carbamazepine as a mood stabilizer).

Symptoms of Posttraumatic Stress Disorder were present. A review of outbursts suggested that they served as methods of avoidance or intimidation when the individual became anxious. Recommendations included continuation of carbamazepine for modulation of aggression and mood; addition of a low dose of an antidepressant for anxiety symptoms; art therapy for past history of sexual abuse and trauma; and detailed behavioural strategies to provide him with safe alternatives to “escape” from anxiety-provoking situations.

Self-Injurious Behaviour

A small percent of individuals with developmental disabilities engage in a particular type of self-directed aggression, often referred to as *self-injurious behaviour* (SIB), which is not usually found within the general population. This may take the form of repetitive head banging, eye gouging, skin picking, rectal digging, and other behavioural repertoires. Individuals with severe Autistic disorder may have higher rates of these behaviours.

The reasons for this form of ongoing self-aggression are not well understood but may include any number of psychiatric disorders, undetected pain, anxiety, distress due to an unrecognized factor, or extreme unhappiness due to environmental causes or an undetected abusive situation. Loss of a family

member or a favourite staff person may spark anger and confusion, with resulting agitation and aggression. In some cases, such behaviour may function as a form of self-soothing under stress.

Successful “management” of aggression and self-injurious behaviour requires knowing what is causing the behaviour, although this can sometimes be difficult to ascertain. A functional analysis of the behaviour can be very helpful by assessing when and where the behaviour happens, in what context it occurs, and possible purposes it may serve. This analysis clarifies the appropriate focus for the intervention, which may be environmental, psychosocial, medical, psychiatric or a combination of these. For some, the right intervention is a change in living situation, a richer schedule of activities, or appropriate medication for a properly diagnosed mental disorder. For others, a more complex strategy of interventions may be required.

CASE EXAMPLE 6

Self-Injurious behaviour, anxiety, and family dynamics

A young woman with Prader-Willi Syndrome and a mild developmental disability was living at home and had a long-standing pattern of intermittent skin picking and gouging, especially of arms and legs, often resulting in secondary infections and antibiotic treatment. She also liked to collect objects, which were typically not of any real value but were often sharp (e.g. paper clips). When anxious or stressed, she would gouge her skin with these found objects, often when she was alone in her bedroom. Negotiating with her to remove the objects from her pockets voluntarily when returning home had been less than successful for many months, and often resulted in both her and her mother feeling very upset.

Psychiatric assessment brought a suggestion for a trial of a Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant for anxiety symptoms and “sticky” perseverative thinking. As well, a referral to a behavioural consultant resulted in her parents realizing that their concern over their daughter’s frequent infections and self-injury had turned into a power struggle, and had resulted in increased restrictions on her activities. A simple script was developed around the pocket emptying and her parents began to increase the number of choices available to their daughter. Over a couple of months, this young woman’s anxiety and perseveration decreased, and she was more willing to empty her pockets when returning home. The request to have her empty her pockets was now made in a low-key way and with a neutral voice. A decrease in incidents of skin picking and infections followed. Both the Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant and the behavioural strategies were needed.

Evaluating the Contribution to Challenging Behaviour of Unrealistic and/or Unachievable Expectations

The less severe the developmental disability and the more subtle the areas of specific deficit, the more likely an individual is to encounter unrealistic social expectations that are formed on the basis of apparent strengths. Likewise, the less disabled an individual is and the more subtle the specific neurodevelopmental deficits that require significant accommodation, the more likely an individual is to encounter the stress of unachievable functional expectations (for example, in managing money, time, and social relationships). This is common in persons with mild developmental disabilities, in high-functioning Autism and Asperger's Syndrome²¹ and in those with Fetal Alcohol Spectrum Disorder (FASD).

Assessment both of relative strengths and of specific neuro-cognitive deficits is required to determine realistic and achievable psychosocial and functional expectations. This could be evaluated through comprehensive neuropsychological and/or functional behavioural analysis.

For those who otherwise appear to function “normally,” needs associated with unique areas of developmental disability can be accommodated by step-by-step breakdown of tasks and by increased prompting to focus on repetition and relevant cues. Enhanced feedback and direct reinforcement can boost motivation and confidence. Needs associated with functional difficulties in self-organization can be addressed by increased structure, routine, and by external guidance to assist people to accomplish what might otherwise be beyond their independent capabilities.

Addressing behavioural challenges first at this level of increased psychosocial support and accommodation can reduce subtle yet predictable sources of frustration, alleviate anxiety, increase trust, and prevent the need for a support person to have to intervene with challenging behaviours. (Ory, 1995)

Policies for Behaviour Interventions and Crisis Training

Policies and procedures are essential to ensure that any use of behavioural strategies conforms to safety, ethical, and accountability practices and makes use of best practice intervention strategies. Planning of behaviour strategies is informed by a proper understanding of the function that the behaviour serves, and

Positive support

For those who are otherwise “high functioning,” this extra level of support must be provided with sensitivity and increased attention to offering support as a choice. There must be respect and high regard for the struggle that accepting support represents to a person who, in other areas, is independent of external support.

²¹ Asperger's Syndrome is included along with autism under Pervasive Developmental Disorders [PDD]. See PDD in the Glossary.

by adequate assessment of communication, medical, psychiatric, and psychosocial factors.

Staff who are required to respond to crisis situations need to have training through an established crisis intervention program. Crisis prevention training supports the work of professionals who work with challenging or potentially violent individuals by providing a relevant, practical behaviour management program. This training is germane for a wide range of providers including administrators and front-line mental health providers. The goal is always to resolve conflict at the earliest possible stage. Such training enhances the care, welfare, safety, and security of staff and those in their care—even during crisis moments. Established training programs have been available for more than 25 years, and are frequently part of training offered by health care organizations as well as by developmental service agencies. These programs are now recognized by many as the international standard for violence prevention and intervention training.

The goal is to promote methods for managing disruptive and assaultive behaviour that are safe, respectful, non-invasive, and compatible with the duty of staff to provide the best care possible in the least restrictive environment.

Inappropriate Sexual Behaviour

People with developmental disabilities often face challenges with sexuality and these challenges can lead to mental health issues. Healthy sexuality for people with developmental disabilities is limited by many factors. Griffiths et al (2002) include an excellent chapter on sexuality and mental health issues in *Dual Diagnosis: An Introduction To Mental Health Needs Of Persons With Developmental Disabilities* and they list the following factors as impediments to sexual health.

1. Persons with developmental disabilities are less likely to have control over their sexuality and reproduction.
2. They often experience restriction, punishment, and recrimination regarding their sexuality, and are further denied privacy, opportunity, knowledge, and choice regarding their sexual expression. They are more often the victims of sexual assault and abuse.
3. They are more likely to experience physical and medical challenges that interfere with their sexual experience and reproduction, including side effects from medications.

These factors may also contribute to the development of inappropriate sexual behaviours for some persons with developmental disabilities. Hingsburger, Griffiths and Quinsey (1991) used the term *counterfeit deviance* to describe

behaviour which, on the surface, appears deviant but, upon investigation, is a result of other factors. They distinguish between sexually inappropriate behaviour and sexually deviant behaviour. Behaviours such as public exposure, inappropriate touching, and even assault may result from living in a system in which appropriate sexual knowledge and relationships are not supported.

The Justice System and People with Developmental Disabilities

A person with a developmental disability, like any other citizen, may become a victim of a criminal act or witness or commit a crime. The response of the justice system and the community will vary depending on the degree of knowledge about developmental disabilities and upon awareness of the need to accommodate the person's disability.

In BC, the Law Courts Education Society of BC has produced a set of teaching modules, *Developmental Disabilities and the Justice System*, to help justice system professionals increase their knowledge about people with developmental disabilities. These modules, which include a professionally produced teaching video with a variety of vignettes, are being taught in BC and across Canada. Information on altering interview style and the need, at times, to involve a support person are just two of the areas focused upon. See <http://www.lawcourtsed.ca/index.cfm?call=0680732c&mnid=307&hl=2&act=main> for details.

Frequent Psychiatric Disorders in People with Developmental Disabilities

Individuals with developmental disabilities can present with signs and symptoms of mental health and addiction disorders that follow DSM IV-TR criteria quite closely, but may often present with a range of atypical symptoms, including aggression²², that may require the clinician to have a broader understanding of *diagnostic equivalents*²³ (see Table 3 on pages 100 and 102 for examples). This section provides a discussion of the similarities and differences in symptom presentation for the most common psychiatric disorders in people with a developmental disability.

²² Psychiatric evaluations are often initiated due to aggressive behaviour. See page 91 for more on this.

²³ Pary, Levitas, & Hurley, 1999

Depression

Individuals with developmental disabilities may present with many typical symptoms and signs of depression. The most common presentation includes:

- sad affect
- social withdrawal
- anhedonia
- tearfulness
- decreased energy
- psychomotor retardation
- depressed appetite
- regression in self-care skills
- sleep disturbance
- hypochondriasis
- aggression
- tantrums
- reduced speech
- increased dependency
- irritability

For this population, symptoms may be more severe and can include²⁴:

- total social withdrawal
- mutism
- psychomotor retardation
- decreased appetite
- weight loss
- severe insomnia
- self-injurious behaviour

Symptoms of hallucinations or delusions may occur more frequently in people with a developmental disability who are depressed.

Reporting feelings of suicidal ideation, self-deprecation, and guilt may be difficult for many. Thus, individuals with developmental disabilities may never meet full DSM-IV-TR criteria. Completed suicides are uncommon, but do occur (Hurley, 1998; 2002).

²⁴ Charlot et al, 1993; Hurley, 1996b; Meins, 1995

Suicidal Thinking, Attempts, and Risk

Suicidal thinking, though, can be quite common in this population and should always be investigated. Asking if someone has ever thought about hurting or killing themselves will frequently yield previously unknown information. Risk-taking behaviour should also be explored (e.g. riding a bike in traffic with eyes closed). The methods chosen may at times not have actual lethal potential, but if the person *thought* they would die by manual self-strangulation, then that should be seen as a significant attempt and should be taken seriously. Assessing for and treating depression and co-morbid physical conditions in people with a developmental disability will result in decreased morbidity.

The following set of four new documents, which address suicide prevention and services, may be accessed on the Ministry of Health Mental Health & Addictions website at <http://www.healthservices.ca/mhd>.

- *Working with the Client who is Suicidal: A Tool for Adult Mental Health & Addiction Services* – provides best practice guidelines for clinicians working with suicidal adults
- *Coping with Suicidal Thoughts* – a brief guide to help individuals decrease thoughts of suicide, intended as a supplement to professional care
- *Hope & Healing: A Practical Guide for Survivors of Suicide* – designed to help survivors through difficult times, focusing on practical matters, including help and resources after a suicide
- *Working with the Suicidal Patient: A Guide for Health Care Professionals* – outlines key tasks and steps for health care professionals to follow in helping clients in acute care settings

Diagnosing Depression in Persons with Developmental Disabilities

For individuals with a severe or profound developmental disability, there is very limited or no access to internal mental life through self-reporting. McBrien (2003) summarized three reviews from the mid-1990s in addition to more recent papers. He concluded that some investigators advocate adherence to standard criteria; others suggest adding new criteria to standard ones; and finally, many use substitute “developmental disability” equivalent criteria, as seen in the tables on the next few pages.

Rating scales have been developed, but there is, as yet, no gold standard diagnostic tool for depression in people with developmental disabilities. However, there was agreement among the three reviews that depression may manifest in atypical ways in people with developmental disabilities. McBrien recommended the development of diagnostic/substitute criteria to reflect this.

DSM-IV-TR Criteria for a Major Depressive Episode and Developmental Disability Equivalents

Numerous reports and studies addressing depression concur that major depressive episodes occur frequently in people with developmental disabilities. Below is a table outlining DSM-IV-TR criteria for a major depressive episode with developmental disability equivalents.

<i>DSM-IV-TR Criteria</i>	<i>Developmental Disability Equivalents</i>
1. depressed or irritable mood	apathetic, sad or angry facial expression; lack of emotional reactivity; upset; crying; tantrums; verbal and physical aggression, carefully judged for context
2. markedly diminished interest or pleasure in most activities	withdrawal; lack of reinforcers; refusal to participate in leisure activities or work; change in ability to watch TV or listen to music
3. significant weight loss; decrease or increase in appetite	tantrums at meals; stealing food; refusing activities; hoarding food in room
4. insomnia or hypersomnia	may or may not be able to self-report sleep problems; if living with others, may report being up at night; others may note going to bed quite late; if living in staffed situation, staff note being up at night; any change in sleeping habits; tantrums or activity during sleeping hours; noted sleeping or napping during the day
5. psychomotor agitation or retardation	pacing, hyperactivity; decreased energy, passivity; development of obsessional slowness in activities of daily living; muteness; whispering; monosyllables; increase in self-injurious behaviour or aggression, carefully judged within context
6. fatigue or loss of energy	appears tired; refuses leisure activities or work; withdraws to room; loss of daily living skills; refusal to perform personal care tasks; incontinence due to lack of energy/motivation to go to bathroom; work production decrease; disinterest in joining activities; just watches TV; sitting for long periods of time
7. feelings of worthlessness	statements such as "I'm stupid" or "I'm bad" or "I'm not normal"
8. diminished ability to think or concentrate	poor performance at work; change in leisure habits and hobbies; appearing distracted
9. recurrent thoughts of death; suicidal behaviour or statements	perseveration on the deaths of family members and friends; preoccupation with funerals

Table 2: DSM-IV-TR Criteria for Major Depressive Episode with Proposed Developmental Disability Equivalents (After Pary, Levitas, & Hurley, 1999)

Bipolar Disorder

Bipolar Disorder is thought to occur at a higher frequency among people with developmental disabilities than in the general population. The presentation of bipolar disorder may be quite different, with more attention paid to the behavioural problems associated with this condition (Cain, Davidson, Burham et al., 2003).

Chronic and severe hyperactivity may be the most salient symptom of mania in severe and profound MR (Sovner & Hurley, 1981; Lowry & Sovner, 1993). People with developmental disabilities also have great difficulty, as stated above, verbalizing the cognitive aspects of the disorder (for example, grandiose thinking).

CASE EXAMPLE 7

Diagnostic overshadowing: cerebral palsy and developmental disability “overshadow” bipolar disorder

A 16-year-old boy with cerebral palsy and a moderate developmental disability was referred due to concerns about his periods of sleeplessness and coinciding increases in “obsessiveness,” intrusiveness, and agitation. He would go for up to three days without sleeping, and these episodes occurred three or four times a year, for a week or two at a time. He was diagnosed with Bipolar Disorder, treated with carbamazepine for mood stabilization, and showed considerable improvement. His parents expressed frustration that, while a mental health disorder was recognized immediately by a specialized mental health service, this had not been considered in previous generic medical treatment.

DSM-IV-TR Criteria for a Manic Episode with Developmental Disability Equivalents

Below is a table outlining DSM-IV-TR criteria for a manic episode with developmental disability equivalents.

<i>DSM-IV-TR Criteria</i>	<i>Suggested Developmental Disability Equivalents</i>
1. mood disturbance	mood is inflated, elated, and expansive; may be irritable or angry; person appears either happy or irritable throughout the day, regardless of circumstances
2. inflated self-esteem or grandiosity	belief or actions may demonstrate that the person thinks he or she can achieve more, in relationship to his/her developmental level - e.g. belief that one is a teacher or staff member; can drive a car or repair a broken TV; or is better than one's peers
3. decreased need for sleep (e.g. feels rested after only three hours of sleep)	person is up at night; is active and moving about the room or house; awakens early or does not get to sleep until quite late; appears energetic next day
4. more talkative than usual or pressure to keep talking	person talks constantly, often seeking attention; cannot listen to others easily; does not really converse but espouses own thoughts
5. flight of ideas or subjective experience that thoughts are racing	ideas flow because of energy; topics are short and often unrelated; cannot respond to topics generated by others easily
6. distractibility (i.e. attention too easily drawn to unimportant or irrelevant external stimuli)	person is distracted by environment, but mainly by own internal energy, compared to usual ability to concentrate on tasks; completes activities of daily living tasks and work tasks quickly and improperly; skips from activity to activity
7. increase in psychomotor agitation or goal-directed activity (socially, sexually, or at work or school)	may work at activities of daily living or work with great speed but little attention to detail or work quality; cannot respond to cues to slow or repeat work if sloppy; may create new tasks, take on projects, or talk about new jobs/work that is not realistic; may be overactive or appear to be in constant motion
8. excessive involvement in pleasurable activities that have a high potential for painful consequence (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)	increase in obvious sexual interests; increased preoccupation with hobbies or general recreational activities; intrusiveness; disinhibition; inability to follow previously-understood rules and limits

Table 3: DSM-IV-TR Criteria for a Manic Episode with Proposed Developmental Disability Equivalents
(After Pary, Levitas, & Hurley, 1999)

Anxiety Disorders

These conditions are thought to be frequently present in the developmental disability client population, but are perhaps among the most difficult to diagnose. Anxiety disorders require greater self-reporting of symptoms, and the identification of anxiety can be difficult for someone with a developmental disability.

With children, youth, and adults, significant anxiety may be reflected as a somatic illness – e.g. a stomach ache. In addition, severe anxiety can lead to behavioural problems. Thus, unless they are aware of this difficulty, families, staff, and caregivers will not recognize the problem as possible anxiety (Masi & Mucci, 2000).

In a clinic study, Stavrakaki and Mintsoulis (1997) found that 27 percent of patients with a developmental disability had anxiety disorders.

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 consensus that these conditions should be treated as they typically would in the general population.

Posttraumatic Stress Disorder (PTSD)

It is likely that individuals who have developmental disabilities are at greater than average risk for experiencing repeated traumatization (Sobsey, et al., 1992).

People with developmental disabilities live, to varying degrees, in a state of dependency on others. The experience of being dependent increases both actual and perceived vulnerability. Furey (1994) reported a survey of 170 people with developmental disabilities who were sexually assaulted. He indicated that approximately half of these individuals had great difficulty securing any treatment for the abuse, and even less received appropriate treatment (Mansell, Sobsey, & Calder, 1992).

The symptoms of PTSD may be quite different from those seen among the general population. People with developmental disabilities may not be able to articulate the event that caused the trauma. Flashbacks and memories may be more vague or distorted, or may be re-experienced and reported as a “recent event,” thus contributing to confusion about the traumatic experience. Increased anxiety and hyper-arousal may present as a “behavioural problem.” Further, due to lack of cognitive reserve and coping skills, brief psychotic episodes may occur (Martorana, 1985; Varley 1984).

CASE EXAMPLE 8

Apparent gender issues actually obsessive component of Asperger’s Disorder

A man in his early twenties with borderline intellectual functioning had been experiencing numerous symptoms of anxiety and obsessional thinking. He was well known to various mental health service providers due to his efforts to find support for gender reassignment. After considerable education and assessment, gender issues were determined to be related to obsessive thinking common to those with Asperger’s disorder, rather than actual gender disorder. Community service providers were open to gender issues being a causal factor, but with considerable expertise the difference was delineated between true gender issues and symptoms of a pervasive developmental disorder (PDD). Client functioning improved with redirection of gender concerns and emphasis on vocational and social functioning.

Psychotic Disorders

Overuse and Misuse of Antipsychotic Medications

Due to the frequent presence of aggression and self-injury, there has been a historical trend toward overuse and misuse of antipsychotic medications in people with developmental disabilities (Branford, 1997; Burd, Williams, Klug, et al. 1997; Branford, 1997; Robertson, Emerson, Gregory et al., 2000). See also *The History Behind the Use of Antipsychotic Medications in Persons with Intellectual Disability: Parts I and II* (Levitas & Hurley, 2006).

These medicines are often prescribed for “behaviour” without an understanding of what lies behind the behaviour. It is essential that health care providers are well trained to ensure that this client population receives appropriate treatment. Poorly trained health providers may not consider different therapeutic supports, or the use of other medicines such as antidepressants or anti-anxiety agents.

People with developmental disabilities may experience psychotic symptoms when under severe stress or during a psychiatric illness. The rate of actual psychotic disorders in this population may be similar to that of the general population, though this is still somewhat controversial as some epidemiological studies suggest an increased prevalence (Deb, Thomson & Bright, 2001). With careful use of diagnostic criteria, a reliable and valid diagnosis is possible (Lee, Friedlander, Donnelly et al. 2003).

There are reports of delusional disorders, such as erotomania, Fregoli (a delusional misidentification syndrome), and folie a deux (Hurley & Moore, 1997; Hurley, 2003; Ulzen, 2003) among this client population. The presentation is often similar to that seen in the general population, with the exception that the delusion itself may be simpler and more childlike; the object of erotomania, for example, may be a fictional cartoon character.

As with other psychiatric disorders, aggression may also be a presenting problem, and people with developmental disabilities may display a high rate of psychotic symptoms occurring with other disorders, such as depression.

The misidentification and over-diagnosis of psychotic symptoms is a major problem in treating individuals with developmental disability (Hurley, 1996a).

Self-talk and Imaginary Friends

During the course of normal development, young children often talk to themselves out loud, engage in solitary fantasy play, or invent imaginary friends. In people with developmental disabilities, these behaviours may continue throughout life and occur much more frequently than among the general population. When the “monologue” is intense, emotional, or occurs without regard to social situation, the caregivers of people with developmental disabilities often mistake the self-talk for hallucinations. Similarly, dramatic fantasy play or engagement with a TV program may be upsetting to caregivers or families.

Adults with developmental disabilities may use self-talk and imaginary friends as a coping mechanism to combat boredom or assuage loneliness long into adulthood. When the person is upset, the character of the conversations may be appropriately angry and emotional. In addition to fighting loneliness, the use of imaginary friends may fill other needs not met in the social environment. **The existence of such a friend, however, must not be taken as evidence, per se, of a psychotic illness.** 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.

Discontinuing Antipsychotic Medication Safely

As awareness of better approaches increases, there is a trend toward discontinuing the “older” antipsychotics. Although this change is desirable, the withdrawal process must be approached cautiously. Currently, with more understanding of receptor blockade in the brain, both the long-term effects of antipsychotic medications on receptor number and function and withdrawal side effects can be better understood.

Withdrawing someone from an antipsychotic medication after they have been using it for many years must be done very slowly (five percent to 10 percent every two months) in order to minimize potentially serious withdrawal effects. When antipsychotic medication is discontinued too quickly, it often results in withdrawal side effects, such as increases in agitation, insomnia, confusion, or aggression. In these cases, service providers, family members, and mental health professionals often conclude that the person obviously “needs” the medication, and it may be reinstated for many more years.

The best approach, if this happens, is to reverse the withdrawal, and then after a month or two to restart it, but at a slower pace and at a much smaller rate of decrease. Anxiety disorders, depression, or Posttraumatic Stress Disorder may be masked by treatment with an antipsychotic medication, and withdrawing the medication may result in a re-emergence of symptoms that, hopefully, will then be recognized and treated appropriately.

With the development of newer medicines, especially the atypical antipsychotics, there has been renewed enthusiasm for the use of these drugs in people with developmental disabilities. Although they are widely used and can be very effective, it is also likely that they are again being overused, as the traditional antipsychotics were in the past. Thus, caution and close monitoring are still required (Friedlander, Lazar, & Klancnik, 2001; Levitas & Hurley, 2006).

Substance Use Disorders

People with developmental disabilities do use addictive substances, though the rate appears to be relatively low compared to the general population. Substance use among persons with developmental disabilities has received little attention from researchers, practitioners, and service planners (Sturmey, 2003), and so it is likely to be underestimated and under-diagnosed.

Prevalence of Substance Use

Tyas and Rush (1993) published a 1988-89 Canadian survey on the use of drug and alcohol services by a wide range of persons with disabilities. The 217

services surveyed reported that 10.3 percent of their clients had some type of disability, but only 2.3 percent were found to have a developmental disability. Clients with a developmental disability were most likely to be identified in assessment /referral services (3.5 percent) and least likely to be identified in detox programs. In another study (Sturmey, 2003), only 8.2 percent of services offered some sort of specialized service for people with a developmental disability.

Westermeyer, Crosby, and Nugent (1998) surveyed 642 persons receiving substance abuse treatment at two university-affiliated clinics. The MR-SD (mental retardation and substance disorder) group comprised 6.2 percent of the total population of the group in treatment. Because people with developmental disability comprise one to three percent of the general population, finding that 6.2 percent of a treatment population also has a developmental disability may indicate a higher than previously realized rate of substance disorders in this population. Further, these authors found that for people with developmental disabilities, psychosocial crises were provoked by relatively little substance use compared to the general population.

Stavrakaki (2002) stated that caffeine and nicotine-related disorders are the most frequently found disorders in this client population and observed that “people with developmental disabilities tend to drink alcohol or use illicit drugs in lower amounts as compared to the general population. As a result, they are more difficult to identify. Often caregivers consider this to be part of the individual’s ‘life pattern’.”

Risk Factors for Substance Use

The movement toward community living has brought greater opportunity for contact with addictive substances. Adolescents and adults with developmental disabilities living in the community may have much greater autonomy, financial means, and opportunity for substance use and misuse. Access to peers and neighbours, greater respect for individual choice, removal of many kinds of restrictions, and greater opportunity for paid work all are benefits of community living but also give rise to greater risk of substance abuse.

According to Sturmey (2003), possible risk factors for substance use disorders in people with developmental disability include:

- ability to independently obtain these substances in the community
- peer and family models for substance use
- ready access
- poor refusal skills
- living independently or with family
- history of suicide attempts
- poor social support

- history of trauma and abuse

An enquiry into **all** substance use (including cigarettes, caffeine, and over-the-counter medicine) could be easily incorporated into history-taking with people with developmental disabilities (Ruedrich, Rossvanes, Dunn, et al., 2003).

Legal and Illicit Drugs and their Effects on the Fetus

Fetal Alcohol Spectrum Disorder is a serious and under-recognized problem for the developing fetus (see pages 24 and 109 for details). In addition, many other drugs used today—both legal (e.g. nicotine) and illicit—also cause numerous problems for the developing fetus. Below are examples of problems caused by some of the more common substances:

- **Cocaine:** increased incidence of bleeding, miscarriage, premature labour, lower birth weight, prematurity; increased risk of bleeding in brain of infant; increased incidence of Sudden Infant Death Syndrome (SIDS); withdrawal symptoms in post-natal period
- **Marijuana:** premature labour, lower birth weight (THC is stored in amniotic fluid); marijuana is often associated with tobacco use, so the effects are combined
- **Amphetamines:** bleeding, early labour, miscarriage; decreased oxygen to fetus; withdrawal pre- or post-natal
- **Heroin and Methadone:** lower birth weight; withdrawal effects after delivery for infant; increased risk of HIV or hepatitis due to contaminated needles
- **Nicotine:** decreased growth; increased miscarriage, still birth, placental problems, premature birth (Alcohol, Other Drugs and Pregnancy – Department of Human Services, Victoria, Australia, <http://www.adf.org.au/adp/index.html>)

Recommended Treatment Strategies for Substance Abuse

Sturmey and his colleagues (2003) summarize appropriate treatment services for people with developmental disabilities and substance use. According to these authors, services must:

- engage the client early in treatment
- make materials easy to read/comprehend
- use repetition of material

- avoid abstract written and spoken material
- keep sessions short (15 to 30 minutes)
- supplement group with individual treatment
- use modeling, rehearsal and feedback to teach skills
- enhance family and other supports
- monitor impact of drug and alcohol use on concurrent medications
- provide follow-up
- monitor relapse
- use concrete short-term goals

Professionals are also advised to consider allowing 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 drug craving, such as yoga and acupuncture, instead of cognitive-based therapies common in the substance use field may be helpful with people with developmental disabilities.

Behavioural Phenotypes

Many specific developmental disabilities are associated with unique behavioural patterns and psychiatric disorders (Dykens, 1995). The concept of *Behavioural Phenotype* was first introduced by Nyhan in 1972 to describe a pattern of behaviour that he felt was very similar in a group of children who turned out to have the same biochemical deficiency (nucleic acid deficiency). A behavioural phenotype, then, is a pattern of behaviour that is reliably identified in groups of children and adults with known genetic disorders or syndromes and is not learned. The field of behavioural phenotypes is rapidly expanding with advances in genetics. The most common and most problematic behavioural phenotypes are described below.

Autism Spectrum Disorder (ASD)/ Pervasive Developmental Disorder

This developmental disability consists of a pattern of abnormal or poor communication, marked impairment in social interaction, restrictive play and/or stereotyped movements and behaviours. Most people diagnosed with Autism Spectrum Disorder 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. These are often the focus of mental health consultation. In addition, there is a significant association between Autism Spectrum Disorder and bipolar disorder in this client population (De Long, 1994; De Long & Nohria, 1994; Lainhard & Folstein, 1994).

There is agreement that Applied Behavioural Analysis²⁵ (ABA) treatment is an essential component of addressing behavioural and mental health problems. (Luiselli, 1998; Gardner, 2002; Griffiths, Gardner, & Nugent, 2001).

For diagnostic standards and guidelines for Autism Spectrum Disorders in BC, see http://www.healthservices.gov.bc.ca/cpa/publications/asd_standards_0318.pdf.

Fetal Alcohol Spectrum Disorder

Prenatal exposure to alcohol can cause Fetal Alcohol Spectrum Disorder (FASD), an “umbrella” term that is gaining prominence internationally to describe the range of effects that prenatal exposure to alcohol can have on the developing fetus and the resultant disabilities that persist in childhood and into adulthood.

Health Canada appointed a National Advisory Committee on Fetal Alcohol Spectrum Disorder in 2001 to determine national diagnostic guidelines for FASD. These Canadian guidelines for the assessment and diagnosis of Fetal Alcohol Spectrum Disorder were published in March 2005 in the Canadian Medical Association Journal (Chudley, 2005). This is an important step in the screening and diagnosis of FASD and will improve standardization of practice and increase accessibility of diagnostic services for both children and adults across Canada.

Permanent neurodevelopmental deficits²⁶, growth impairment, and other birth defects are considered the *primary disability* characterizing Fetal Alcohol Spectrum Disorder, while *secondary disabilities* (many of which can be mediated by proper interventions and support) can include²⁷:

- high rate of mental health/addiction problems and disorders (90 percent)²⁸
- disrupted school experience (60 percent)

²⁵ *Applied behavioural analysis encompasses learning theory and an understanding of what leads to or doesn't lead to acquisition of new skills. It is a practical approach to teaching new skills and decreasing maladaptive behaviours, as well as supporting the maintenance of previously learned skills. It is intensive, one-to-one structured, repetitive learning.*

²⁶ *Brain damage*

²⁷ *Streissguth & Kanter, 1997.*

²⁸ *Mental health problems and disorders in this population can include suicide and suicide attempts, depression, anxiety, and attention-deficit hyperactivity disorder.*

- trouble with the law (60 percent)
- confinement in inpatient units for mental illness/substance abuse or incarceration for a crime (50 percent)
- inappropriate sexual behaviour (50 percent)
- alcohol or drug use problems (50 percent)
- dependent living (80 percent)
- problems with employment (80 percent)

The chart below illustrates these challenges graphically.

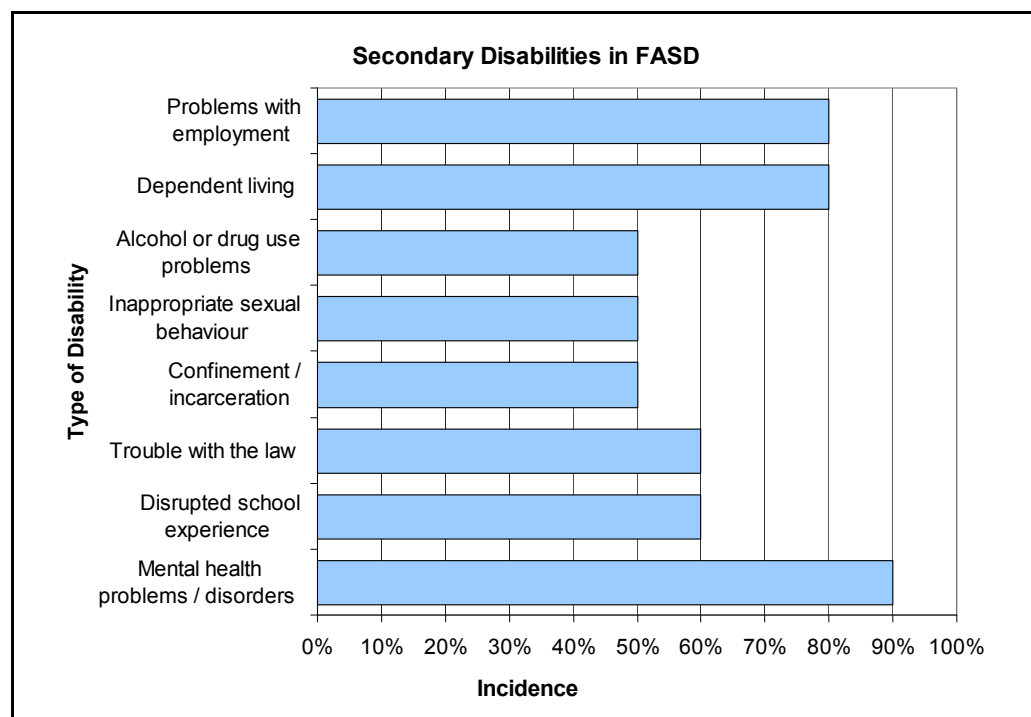


Figure 5: Incidence of Secondary Disabilities in FASD

Early diagnosis (before age six), together with proper support and intervention, will result in fewer secondary disabilities for persons with FASD. 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.

People with FASD may or may not have MR (IQ less than 70) but most tend to have a marked discrepancy between IQ and adaptive functioning (see page 75), with the latter almost always being lower than IQ, and adaptive function often falling below 70.

FASD is not an inherited condition but can become “multigenerational,” when women affected by FASD **and** who use alcohol become parents themselves. FASD occurs in all cultures and can occur at all levels of financial means. Societal awareness and acceptance of the toxic effects of alcohol on prenatal and post-natal development is one of the keys to preventing FASD. It is equally important, however, to identify and support girls and women (and their partners) of childbearing years who are struggling with substance use, abusive home lives, or lack of access to or knowledge about birth control. When someone is diagnosed with FASD, it is important to consider the needs of both mother and child. The highest predictor of having a child with FASD is already having a child with FASD.

Lesch-Nyhan Syndrome

Lesch-Nyhan Syndrome is a genetic disorder caused by an inborn error of metabolism. Individuals with this condition begin to engage in severe self-mutilation as young children. For example, they may bite off their tongue or gouge their eyes out. Due to the severity of this behavioural disorder, they require extensive psychiatric and rehabilitative care. Some work has suggested anxiety as a mediator or cause for this behaviour, as well as social reinforcement. Most children need mechanical restraint, as mutilation continues during sleep. This condition is typically accompanied by cerebral palsy, and most people with Lesch-Nyhan Syndrome die by early adulthood.

Prader-Willi Syndrome

This condition has an unknown etiology, although most individuals have an identified deletion on chromosome 15. These individuals are slow and motorically floppy as infants, and in early childhood develop severe appetite deregulation that often leads to morbid obesity (Dyken & Rosener, 1999). People with Prader-Willi Syndrome may be so driven that they may eat from trash bins or consume non-edible food. In addition, they may have associated compulsions, skin-picking, and some develop a psychotic form of bipolar illness. Prevention of morbid obesity is essential. Most individuals need residential care eventually and programs that control all food access. Intervention remains challenging in many cases and should include coordinated medical, behavioural, and psychiatric treatment.

FASD and the Justice System

A BC study of the frequency of FASD in the youth criminal justice system provided insights into the occurrence of FASD within the legal system. This one-year study found that 23.3 percent of youth remanded to a forensic psychiatric inpatient assessment unit were found to have a Fetal Alcohol Spectrum Disorder, which is five to 25 times the accepted world-wide incidence of FASD (Fast, Conry & Looock, 1999). A recent book also by these BC authors, *Fetal Alcohol Syndrome and the Criminal Justice System* (Conry & Fast, 2000), provides further detailed information about FASD and points out the challenges people with disabilities such as FASD have in the criminal justice system, whether they are victims, witnesses, or the accused in criminal cases and child custody cases.

Down Syndrome

Down Syndrome is the most common genetic cause of developmental disability. It is the most frequently occurring chromosomal abnormality, happening once in approximately every 800 to 1,000 live births. Down Syndrome has three forms:

- extra chromosome 21 (about 95 percent of people with Down Syndrome)
- translocation of chromosome 21 material (five percent)
- partial trisomy 21 (rarest)

Individuals with Down Syndrome are prone to develop impaired thyroid function (hypothyroidism) and are more prone to develop Alzheimer-like dementia at an earlier age, associated with accelerated aging problems. Although many individuals eventually show clinical signs of Alzheimer-like dementia—rates may be at about 80 percent by age sixty—it is not universal. There is evidence, however, that individuals with Down Syndrome have a behavioural phenotype (Chapman & Hesketh, 2000).

People with Down Syndrome are also prone to a high rate of depression and anxiety disorders. If depressed, they are more likely than other individuals with developmental disability to be unresponsive to antidepressant medication (Collacott & Cooper, 1994; Pary, 2002). In addition, a number of clients develop *obsessional slowness*, a severe obsessive-compulsive disorder that is exceedingly rare in the general population and not reported in people with developmental disabilities who do not have Down Syndrome. (Charlot, Fox & Friedlander, 2003) Treatment must include medication trials as well as behavioural consultation and positive support.

Williams Syndrome

People with this genetic condition can exhibit a range of abilities from severe developmental disability to no cognitive impairment. These individuals have preserved verbal and linguistic skills in contrast to very poor organizational skills. They are overly social, highly anxious, and can have compulsive and perseverative behaviours. Their anxiety may respond to pharmacotherapy treatment (Dyken, 1995; Dyken & Rosener, 1999; Dyken, 2001).

22q Deletion Syndrome

This condition consists of three overlapping disorders that make up the 22q deletion syndrome, with an incidence of one per 3,000 to 4,000 in the general population. Persons with *Velocardiofacial syndrome* (VCFS 22q11 deletion) have characteristic facial features, learning problems (40 to 50 percent have mild to moderate MR), cardiac abnormalities, and cleft palate or *velopharyngeal* incompetence.

Associated with Velocardiofacial syndrome (VCFS) is a high incidence of attention deficit disorder and social difficulties. Treatment with stimulants such as methylphenidate may cause adverse reactions (O'Brien, G. 2002). Up to 70 percent of those with VCFS have mood lability and would fit on the broad spectrum of bipolar disorders (Hagerman, R. 1999). There are reports of up to 30 percent of persons with VCFS demonstrating psychotic symptoms in adolescence, though these symptoms could be part of a bipolar disorder. Persons with VCFS have been misdiagnosed with schizophrenia when they actually have a bipolar disorder.

Fragile X Syndrome

This is the most common inherited genetic disorder and is caused by a *trinucleotide repeat* (CGG) in expansion in the Fragile X mental retardation 1 gene (FMR1) at chromosome Xq27.3 (Hagerman & Hagerman, 2002). In its full form, it affects only males, but lesser forms of the condition are found in female family members as well. This condition usually results in mild to moderate developmental disability. Fragile X Syndrome is associated with hyperactivity and some autistic features, as well as with attention-deficit hyperactivity disorder (ADHD), hyper-arousal, anxiety, and aggression related to mood lability. These associated conditions are treated with behavioural therapy as well as medications such as stimulants (e.g. dextedrine or methylphenidate), Selective Serotonin Reuptake Inhibitor antidepressants, and mood stabilizers (Amara, Lacey, & Hagerman, 2001). In addition, deficits in social interaction, gaze-avoidance, and unusual responses to stimuli may also suggest an atypical pervasive developmental disorder associated with this syndrome (Levitas, 1996). (44-64)

CHAPTER 6: Prevention and Social Determinants

Health Promotion, as defined by the World Health Organization (WHO), is the process of enabling people to increase control over, and to improve, their health. WHO defines mental health as a state of physical, mental, and social well-being, and not merely the absence of disease or infirmity. People with developmental disabilities often are not able to achieve or retain the control of their lives that non-disabled persons assume is theirs by right. For many, a life-long network of support is needed in order for them to even come close to achieving the above goals of mental health within the context of health promotion.

The Five Tenets of Health Promotion

The five basic tenets of Health Promotion are derived from the *Ottawa Charter for Health Promotion* (WHO, November 1986). Application to the lives of people with developmental disabilities is very relevant, though success requires that the individual as well as the **community** of citizens and government act together. Following are the five tenets with brief examples relevant to people with developmental disabilities.

1. **Building healthy public policy:** Ensures equity of access to services and treatments; for example, children with Autism spectrum disorders have access to early intervention programs to improve their social and communication abilities.
2. **Creating supportive environments:** Within schools and colleges, children, youth and adults with developmental disabilities are allowed to learn at their own pace and to share a common experience with their peers.
3. **Strengthening community action:** Parents of children with developmental disabilities have advocated through community action initiatives to have their institutionalized children and adult children returned to the community and to obtain access to “regular” community supports and services.
4. **Developing personal skills:** Participating in Special Olympics has an impact on an individual’s self-esteem, pride in accomplishment, team play skills, confidence, and assertiveness.

5. **Reorienting health (and social) services:** The movement toward community living and away from institutional living for people with developmental disabilities required and continues to shape appropriate health and community responses.

For further information on Health Promotion research, see

<http://www.ihpr.ubc.ca>. For the Ottawa Charter, see

http://www.euro.who.int/eprise/main/WHO/aboutwho/policy/20010827_2.

Prevention of Mental Health Problems in Developmental Disability

Prevention consists of activities directed toward decreasing the probability of specific illnesses or dysfunctions in individuals, families, and communities. For all individuals—but particularly for individuals with developmental disabilities—maximizing prevention across all three levels of care (primary, secondary, and tertiary) can significantly impact outcomes, which carry through to adulthood. Child development centers, public health nurse screening of infants, infant stimulation programs, and assessment and monitoring by family physicians and paediatricians contribute to childhood prevention. Prevention focused on developmental disabilities, given the overlap in biomedical and psychosocial causes of mental disorders, will also reduce the prevalence of mental health disorders for people with developmental disabilities. Additionally, secondary and tertiary prevention relevant to the field of mental disorders in the general population also applies to those with developmental disabilities.

Early Identification and Intervention

Early identification and intervention programs have significant positive impact on long-term outcomes and can mediate the biological risk factors related to cognitive development. The causal chains are multifaceted, dynamic, and complex. As such, intervening anywhere in the chain may have dramatic effects on several levels of health outcomes. The *Florida 2010* goal for children and youth observes that: “Young children with disabilities and conditions which place them at risk for developmental delays are at greater risk of child abuse, and their families are at greater risk for divorce and suicide. While raising young children is challenging for anyone, families with an infant who has special health care needs often feel overwhelmed, frightened, a personal failure, and helpless. They are often unable to find supports such as preschool or child care to allow them time to go to school, work, or even go shopping. Early intervention can help families learn to cope and take charge as the most important partner in the child's developmental intervention plan.”

(<http://www.doh.state.fl.us/family/childhealth/childreport/>)

Primary Prevention

Primary prevention activities such as immunization and promotion of healthy pregnancies are aimed at intervention before pathological changes have begun and during the window of susceptibility. For example, in Seattle, Washington, intensive intervention with women of child-bearing age at high risk of drug and alcohol use and poor nutrition has been supported through targeted intensive community programs under *The Birth to Three Advocacy Model* (Grant, Ernst, Streissguth & Porter, 1997).

Interventions aimed specifically at changing the genetic endowment of a child are difficult to implement, and few options are available. More potential exists for preventing teratogenic effects (e.g. prenatal alcohol exposure) and other health-related outcomes. Through new developmental disability research, we are realizing significant gains in opportunities as the result of early intervention services.

Secondary Prevention

Secondary prevention activities are aimed at early detection of disease or disability, and prompt treatment or intervention to cure disease during its earliest stages or to slow its progression, prevent complications, and limit disability when a cure is not possible. Screening programs and interventions aimed at finding and designing environments that promote optimal development are well known and can be put in place if appropriate resources are available (Zoritch, Roberts and Oakley, 1998; Rogers, 1998).

Early intervention, accurate diagnosis, and use of the most effective interventions have been common themes in recent years, with the recognition that these strategies can reduce the secondary disabilities associated with untreated mental illness such as suicide attempts or completions, substance abuse, and family stress and breakdown. In developmental disability, prevention of additional disabilities and promotion of social relationships can have a dramatic decrease in the level of clinical and support services required later in life.

One of the most common examples is Autism Spectrum Disorder. Children with this disorder benefit from intensive intervention from the time of diagnosis. These children must be assessed for communication, social, and academic delay, and have remediation interventions available from an early age. Through applied behaviour analysis and other emerging interventions, long-term outcomes such as improved social relationships, decreased self-injurious behaviour, and improved functional language mean a more inclusive life for many individuals (Smith, Eikeseth, Klevstand et al., 1997).

Milestones and Risks

Development is an ongoing process that begins with conception and continues throughout life. Many complex factors may challenge or disrupt development and result in atypical development. Professionals need knowledge of normal developmental sequences to identify atypical development and to seek appropriate support and habilitation for families and young children. The degree and severity of a disability are in part determined by the access to services for the condition, the effectiveness of those services, and the accommodations made by the child's parents, school and community. Critical developmental milestones are well known in the early years up to age six. Several other transition points are of particular importance for this client population. These include transition from home to early support services outside the home, child care, transition to preschool, transition to middle and high school, transition from high school to adult services, and transition from dependent to independent living or supported independent living. Service systems attending to these transitions will maximize the individual's ability to retain functional skills (Levitas & Gilson, 2001).

Tertiary Prevention

This level of prevention limits the effects of disease and disability for people in the earlier stages of illness and provides rehabilitation for people who already have residual damage. For example, a child with Down Syndrome may have chronic ear infections which must be closely followed and, if hearing impaired, must undergo special interventions for the hearing deficit. Thus, individuals with developmental disability must receive ongoing access to appropriate assessment and review, ensuring best clinical practice.

Continuity of Care

Ensuring continuity of care has an impact on the level of stability of the individual. For many, change in the care team or care setting can be detrimental, but may be buffered by adequate transition planning and knowledge of the individual's specific care needs. Changes in these psychosocial and environmental variables can end up precipitating inpatient admissions or the need for other mental health responses. Stabilization efforts can include support for youth staying in school, and specific social supports which prevent secondary disability (for example, in fetal alcohol spectrum disorders).

Social Determinants of Health

The social aspect of any person is key to understanding his or her health status and liabilities. Social supports and social issues should therefore be included in any efforts to support people with developmental disabilities and mental health needs. Social supports are very important to the health of all people, but for people with developmental disabilities social supports may be difficult to foster and develop. There are practical and emotional factors to social supports. Practical aspects of social supports can provide concrete items such as money, housing, jobs, food, child care, clothing, nursing care, fun, guidance, transportation, protection, connections, and opportunities to develop skills. The emotional side of social supports can boost self-esteem, lower anxiety, minimize stress, increase the sense of security, build strengths, empower, and create hope.

Nugent and Lunskey (2002) also describe the impact of negative social supports on people with developmental disabilities:

“There is some suggestion that the presence of stressful or negative relationships in the life of a person with a developmental disability causes more distress than the absence of good relationships. So, when we talk about social support, we have to think not only about what positive relationships are there for our clients, but also how many difficult interactions they have to endure each day. Often, individuals

with developmental disabilities find themselves faced with negative social interactions that they cannot escape. They may not be able to escape due to limited options in terms of vocational and residential settings” (363).

Education

Throughout the school years, children with developmental disabilities must receive appropriate educational services to enhance their ability to function as adults. Schools also teach children how to operate in society, and help them to develop friendships. The education system has at its disposal remedial programs for children with various forms of learning disabilities that may improve long-term outcomes into adulthood. Transitions between graduation and community vocation are challenging, and the impact of this transition can be minimized through planning and links to continued placements in specialized college programs and day programs where the emphasis is on learning social skills and functional adaptive skills.

Employment

As children mature into adults, the next phase is preparation for employment or supported employment. Jobs provide people with dignity, increased self-esteem, empowerment, and remuneration so that they can feel they are productive members of society. Assessment is an essential and integral part of both pre-employment and supported employment services to identify strengths and weaknesses and to facilitate seamless movement among the various employment services.

Physical Environment

A person’s living situation has an impact on emotional well-being and, for some individuals, home environment may also have an impact on decreasing or increasing mental health problems. Some individuals may have very sensitive hearing or be bothered by even ordinary noise levels. A noisy and/or busy home environment can increase anxiety, frustration, and stress levels and may affect sleep patterns. The need for quiet, low-stimulation areas in a home—whether it is a family home, private caregiver, or group home—may be essential to an individual’s well-being, yet may not always be available. In a group home, where there may be three to four individuals with mental health needs and/or challenging behaviours, one individual in crisis will have an effect on the other residents of the home. Having areas in the home that are sound-proofed or isolated may help to decrease stress on other residents.

Balancing safety with a home-like atmosphere is also an important consideration in designing or choosing a living environment. Open sight lines and the use of plywood instead of drywall are modifications that are not obvious but which support a safer environment. People who are not able to safely navigate traffic on their own but who are at risk of impulsively leaving home may require warning alarms placed on doors, or a home designed with safe access to the yard and garden but not the road. The right to privacy and “a room of one’s own” also needs to be considered for people with developmental disabilities, and is what most of the general population takes for granted.

Income

This client population requires adequate income and resources to access appropriate housing, maintain an adequate diet, and have access to community resources and social and recreational activities. A stable source of funding is essential for these individuals to function well in the community. Volunteer program supplements such as the therapeutic volunteer program administered by health authorities can provide modest additional income, a feeling of contributing, and opportunity for community contacts.

CONCLUSION

A continuum that encompasses primary, secondary and tertiary care services for children, youth and adults with developmental disability is needed within mental health and addiction programs. This should be enhanced by a continuum of community-based services, provided through formal developmental disability programs enhanced by access to generic and non-governmental community services.

The level of a person's IQ does not predict prognosis or response to treatment for mental or physical disorders. Knowledge of the level of a client's adaptive function is important in order to determine the degree of support that is needed for follow-up care.

People with developmental disabilities can be susceptible to the full range of psychiatric disorders and require the same access to treatment and support as other individuals receiving services from mental health and addiction services.

Health care providers throughout the system of care will benefit from specific training about the physical and mental health needs of this client population.

The mental health of persons with a developmental disability should be addressed through timely identification, assessment, diagnosis, treatment, and ongoing appropriate care of their mental health conditions, thus reducing the downstream impact on services over the long term.

Measuring key mental and physical health indicators for this client population is essential for working towards improved health outcomes.

In planning mental health and addiction services, it is essential that individuals and their families are maintained as a central focus in order to achieve high quality and sustainable mental health and addiction services for this client population.

In order to ensure sustainable long-term services to people with developmental disabilities and mental health and addiction needs, service agreements should be in place between the government bodies responsible for developmental services and those responsible for mental health and addiction services. Clarity of the mandates of service providers is essential to ensure consistent interpretation and application of policies for this client population.

APPENDIX A: Resources

Assessment Resources

Aberrant Behavior Checklist - Residential & Community (ABC)

Aman, M. G., & Singh, N. N. (1986, 1994)
Aberrant Behavior Checklist Manual, and
Aberrant Behavior Checklist Community Supplementary Manual
Slosson Educational Publications, East Aurora, NY
<http://www.slosson.com>

Adaptive Behavior Scale - Residential and Community, 2nd Edition

Nihira, K., Leland, H., & Lambert, N. (1992)
Pro-Ed, Austin, TX
<http://www.proedinc.org>

CANDID: Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities

Xenitidis, K., Slade, M., Thornicroft, G., & Bouras, N.
Gaskell Publishing, Royal College of Psychiatrists
http://www.rcpsych.ac.uk/publications/gaskell/99_4.htm

Developmental Behavior Checklist

Einfeld, S. J. & Tonge, B. J. (1994)
Manual for the Developmental Behaviour Checklist (Primary Care Version)
University of New South Wales and Monash University.
<http://www.med.monash.edu.au>

Dementia Scale for Down Syndrome

Gedye, A. (1995)
P.O. Box 39081, Vancouver, BC, Canada V6R 4P1

Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD), PAS-ADD Checklist, The Mini PASS-ADD Interview Pack

Moss S. C., Goldberg, D, Prosser H., Costello H., Simpson N. & Patel P.
Hester Adrian Research Centre, University of Manchester, Manchester, UK
Brighton, UK: Pavilion Publishing.
Jackie Hales, Hester Adrian Research Centre. The University of Manchester, Oxford Road,
Manchester, UK, M12 9PL, fax 01612 75333
<http://www.pasadd.co.uk>

Reiss Screen for Maladaptive Behavior

Reiss, S. (1988)
Test Manual for the Reiss Screen for Maladaptive Behavior.
International Diagnostic Systems, Worthington, Ohio

Reiss Scales for Children's Dual Diagnosis

Reiss, S., & Valenti-Hein, D. (1990)
Reiss Scales for Children's Dual Diagnosis.
International Diagnostic Systems, Inc., Worthington, Ohio
<http://www.IDSpublishing.com>

Scales of Independent Behavior-Revised (SIB-R)

Bruininks, R. H., Woodcock, R. W., Weatherman, R. F. & Hill, B. K. (1996)
Riverside Publishing Company, Chicago, IL
Spring Lake Dr., Itasca IL, 60143-2079 USA
1-630-467-7000, 425
<http://www.riversidepub.com>

Supports Intensity Scale (SIS).

Thompson, J. R. et al. (2004)
Adjunct to adaptive behaviour scales as it makes the needs of the person the point of departure for planning supports and services
American Association on Mental Retardation, Washington, DC
<http://www.aamr.org>

Vineland Adaptive Behavior Scales

Sparrow, S. S., Balla, D. A. & Cicchetti, D. V. (1984)
AGS Publishing – American Guidance Service
4201 Woodland Rd , Circle Pines , MN 55014-1796 USA
1-651-287-7220
<http://www.agsnet.com>

Publications

Practice Guidelines

Deb, S., Matthews, T., Holt, G., & Bouras, N. (Eds.). European Association for Mental Health in Mental Retardation (2001). *Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability*. London: Pavilion Press

Griffiths, D., & Gardner, W. I. (2002). Programs and intervention approaches for the treatment of persons with dual diagnosis: A summary. In J. W. Jacobson, S. Holburn, J. A. Mulick, (Eds.), *Contemporary dual diagnosis: MH/MR. Service models, Volume II: Partial and support services* (pp. 141-149). Kingston, NY: NADD Press.

Hamilton-Kirkwood, L., Ahmed, Z., Allan, D., Deb, S., et al. (Eds.). NHS Wales. (2001). *Health evidence bulletins Wales: Learning disabilities (intellectual disability)*.

Mansell, S. (1996). Considerations for providing therapy to people with developmental disabilities who have been sexually abused. *Proceedings of the 13th Annual Conference of the National Association for the Dually Diagnosed, Vancouver, BC*. Kingston, NY: NADD.

Ohio Department of Mental Retardation and Developmental Disabilities Advisory Committee. (2000) *Clinical best practices for serving people with developmental disabilities and mental illness: Report and recommendations*. Columbus, OH: Ohio Department of Health.

Szymanski L, & King, B. H. (1999). Practice parameters for the assessment and treatment of children, adolescents and adults with mental retardation and co-morbid mental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(12), 5S-31S.

Professional Books

Bambara, L., & Knoster, T. (1998). *Designing positive behavior support plans*. Washington, DC: AAMR Press. <http://www.aamr.org>

Bouras N. (Ed.). (1999). *Psychiatric and behavioural disorders in developmental disabilities and mental retardation*. Cambridge: Cambridge University Press.

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

Davidson, P. W., Prasher, V. P., & Janicki, M. P. (2003). *Mental health, intellectual disabilities and the aging process*. UK: Blackwell Publishers. ISBN 1405101644.

Dosen, A., & Day, K. (Eds.). (2001). *Treating mental illness and behavior disorders in children and adults with mental retardation*. Washington, DC: American Psychiatric Press. <http://www.psych.org>

Planning Guidelines for:

Mental Health and Addiction Services for Children, Youth and Adults with Developmental Disability

Dinerstein, R. D., Herr, S. S., & O'Sullivan, J. L. (Eds.). (1998). *A Guide to Consent*. Washington, DC: American Association on Mental Retardation. <http://www.aamr.org>

Emerson, E. (2001). *Challenging Behaviour: Analysis and intervention in people with intellectual disabilities* (2nd ed.). Cambridge: Cambridge University Press.

Gardner, W. I. (2002). *Aggression and other disruptive behavior challenges: Biomedical and psychosocial assessment and treatment*. Kingston, New York: NADD Press. <http://www.thenadd.org>

Gedye, A. (1998). *Behavioural diagnostic guide for developmental disabilities*. Vancouver, BC: Diagnostic Books. Available from: P.O. Box 39081, Point Grey, Vancouver, BC V6R 4P1, Canada.

Griffiths, D., Gardner, W. I., & Nugent, J. (2001). *Behavior supports: Individual centered behavioural interventions: A multimodal functional approach*. Kingston, NY: NADD Press. <http://www.thenadd.org>

Hagerman, R. J. (1999). *Neurodevelopmental disorders, diagnosis and treatment*. Oxford, UK: Oxford University Press.

Hanson, R., Wiesler, N. A., & Lakin, C. (2002). *Crisis: prevention and response in the community*. Washington, DC: AAMR Press. <http://www.aamr.org>

Jacobson, J., & Mullick, J. (Eds.). (1996). *Manual of diagnosis and professional practice in mental retardation*. Washington, DC: American Psychological Association. <http://www.apa.org>

Jacobson, J. W., Holburn, S., & Mullick, J. A. (Eds.). (2002). *Contemporary dual diagnosis: Mental health/mental retardation. Residential and day services - Volume 1*. Kingston, NY: NADD Press. <http://www.thenadd.org>

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L'Abbé, Y., & Morin, D., (1999). *Comportements agressifs et retard mental: Compréhension et intervention*. Eastman, Québec: Éditions Behavioral, Inc. Available from: Bibliothèque Nationale du Canada. ISBN: 2-76629-0040-7.

Mansel, S., & Sobsey, D. (2001). *Counselling people with developmental disabilities who have been sexually abused*. Kingston, NY: NADD Press. <http://www.thenadd.org>

Nickel, R. E., & Desch, L.W. (Eds.), (2000). *The physician's guide to caring for children with disabilities and chronic conditions*. Baltimore: Paul H. Brookes. <http://www.pbrookes.com>

O' Brien, G. (Eds.), (2002). *Behavioural phenotypes in clinical practice*. Cambridge, UK: MacKeith Press. Distributed by Cambridge University Press.

Ory, N. (1995). *Working with people with challenging behaviors - A guide for educators and caregivers*. Canada: Challenging Behavior Analysis & Consultation, 982 Owlwood Place, Victoria, BC V8X 4T3. ISBN 0-9684565-0-2.

Prasher, V. P., & Janicki, M. P. (Eds.). (2003). *Physical health of adults with intellectual disabilities*. UK: Blackwell Publishers. ISBN 1405102195.

Royal College of Psychiatrists. (2001). *DC-LD Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/ mental retardation*. London: Gaskell, Royal College of Psychiatrists. Distributed in North America by the American Psychiatric Press. <http://www.psych.org>

Reiss, S. (1994). *Handbook of challenging behavior*. Worthington, OH: International Diagnostic Systems. <http://www.IDSpublishing.com>

Reiss, S., & Aman, M. (Eds.). (1998). *The international consensus handbook: Psychotropic medications and developmental disabilities*. Columbus, OH: Ohio University Press. Distributed by American Association on Mental Retardation. <http://www.aamr.org>

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Streissguth, A., & Kanter, J. (Eds.). (1997). *The Challenge of Fetal Alcohol Syndrome: Overcoming secondary disabilities*. Seattle, WA: University of Washington Press. <http://www.washington.edu/uwpress/>

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Walsh, P. N. (2002). *Health and women with intellectual disabilities*. UK: Blackwell Publishers. ISBN 1405101032.

Wiesler, N. A. & Hanson, R. H. (Eds.). (1999). *Challenging behavior of persons with mental health disorders and severe developmental disabilities*. Washington, DC: American Association on Mental Retardation.

Journals & Special Journal Issues

Developmental Disabilities Bulletin. Published twice annually by the J. P. Das Developmental Disabilities Centre, University of Alberta, Edmonton, AB, Canada T6G 2G5. <http://www.ualberta.ca>

Journal of Intellectual Disability Research. Twice yearly, a special issue on mental health is produced. Blackwell Publishers, London, UK. <http://www.blackwellpublishing.com>

Mental Health Aspects of Developmental Disabilities. Quarterly journal produced by Psych-Media, Inc., Bear Creek, NC, USA. 27207. <http://www.mhaspectsofdd.com>

Planning Guidelines for:

Mental Health and Addiction Services for Children, Youth and Adults with Developmental Disability

The NADD Bulletin. Published bi-monthly. (NADD is an association for persons with developmental disabilities and mental health needs.) NADD also publishes many books on developmental disability and mental health. <http://www.thenadd.org>

Journal Special Topic Issues

Hatton, C., Blacher, J., & Llewellyn, G. (2003). Special issue on family research. *Journal of Intellectual Disability Research*, 47, 215-399. <http://www.blackwellpublishing.com>

Levitas, A. S., Hurley, A. D., & Pary, R. J. (Eds.). (2001). The psychiatric diagnostic interview evaluation in patients with mental retardation and developmental disabilities. *Mental Health Aspects of Developmental Disabilities*, 4, 1-47. <http://www.mhaspectsofdd.com>

Levitas, A. S. (Ed.). (2001). Behavioral phenotype. *Mental Health Aspects of Developmental Disabilities*, 4, 129-165. <http://www.mhaspectsofdd.com>

Luiselli, J. (Ed.). (2000). Diagnosis, assessment and treatment of sexual deviance and sexually offending behavior in people with developmental disabilities. *Mental Health Aspects of Developmental Disabilities*, 3, 41-80. <http://www.mhaspectsofdd.com>

Mikkelsen, E. (Ed.). (1997). Psychiatric assessment of the person with mental retardation. *Psychiatric Annals*, 27, 160-221.

Pary, R. J. (Ed.). (2002). Mental health problems in Down syndrome. *Mental Health Aspects of Developmental Disabilities*, 5, 33-67. <http://www.mhaspectsofdd.com>

Rush, J., Frances, A., Aman, M. G., et. al. (Eds.). (2000). Special issue: expert consensus guidelines on the treatment of psychiatric and behavioral problems in mental retardation. *American Journal on Mental Retardation*, 105, 1-228. <http://www.aamr.org>

Sovner, R. (Ed.). (1996). Neuropsychiatric syndromes in the developmentally disabled. *Seminars in Clinical Neuropsychiatry*, 1, 89-167. Philadelphia, PA: W.B. Saunders, Co.

Clinical Information WEB Sites

General Information on Developmental Disabilities

The Family Village

<http://www.familyvillage.wisc.edu/index.htmlx>

This is a web site for clinicians, non-specialists and families, offering a searchable database on genetic syndromes and other medical, educational and vocational issues relevant to persons with MR and their families. It is maintained by the Waisman Center of the University of Wisconsin Medical Center, in the United States. Clinical descriptions of syndromes in language accessible to non-specialists and families, and

links to support groups and newsletters are among the many useful and user-friendly features of this web site.

Genetic Conditions & Syndromes

OMIM (Sometimes simply said as a word, “Omim”)

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=omim>

OMIM is the acronym for the online version of McKusick’s comprehensive text, *Mendelian Inheritance in Man*. This resource is maintained by US Federal Government’s National Center for Biotechnology Information at the National Library of Medicine. Constantly updated as new information becomes available, the database can be searched by name of syndrome or location of chromosome abnormality. Within each entry, the information available varies from the clinically relevant and immediately useful to the highly technical (useful only to specialists and research geneticists), with the useful clinical information at the head of each entry. Each entry offers links to various levels of information. Pages are printable and can be added to charts. References can be followed, often to other online sources. Photographs and other images may be linked in some entries, some of which may contain links to relevant family and support groups and other relevant web sites. Other sites often refer to a syndrome’s “OMIM number.”

Alliance of Genetic Support Groups

<http://www.geneticalliance.org/>

This organization comprises groups devoted to each particular syndrome, and can be reached by phone, in the US, at 202-966-5557, by email at info@geneticalliance.org, or through its web page at the address above.

The Society for the Study of Behavioural Phenotypes

<http://www.ssbp.co.uk/files/about.htm>

This site provides fact sheets on many syndromes.

Electroconvulsive Therapy (ECT) Guidelines in BC:

Electroconvulsive Therapy Guidelines

http://www.healthservices.gov.bc.ca/mhd/pdf/ect_guidelines.pdf

Electroconvulsive therapy guidelines for health authorities in British Columbia.

The reach and usefulness of these guidelines has been enhanced by having them translated into Chinese and Punjabi and they can be accessed at the above web site. Complementary videos, one for health care providers and one for clients and families, were also prepared. They have been translated as well and disseminated to hospitals where ECT is provided and to mental health centres.

Fetal Alcohol Spectrum Disorder Resources

Provincial FASD Prevention Consultant

Anne Fuller

Early Childhood Development Branch, Ministry of Children and Family Development

P.O. Box 9719, Stn. Prov. Govt., Victoria, BC V8W 9S5

Planning Guidelines for:

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Phone: (250) 387-5947 Fax: (250) 356-0399

Email: Anne.Fuller@gov.bc.ca

The Asante Centre for Fetal Alcohol Syndrome

Maple Ridge, BC

<http://www.asantecentre.org/>

BC Government FASD Strategic Plan

Released September 2003.

<http://www.gov.bc.ca/fasd/>

Directory of FAS/FAE Information and Support Services in Canada

Provides an extensive list of BC-based groups.

<http://www.ccsa.ca/pdf/ccsa-008036-2003.pdf>

BC Aboriginal Network on Disability Society (BCANDS)

<http://www.bcands.bc.ca/faskit.html>

FAS/FAE Support Network of BC

<http://www.fetalalcohol.com>

Sunny Hill Centre for Children

<http://www.cw.bc.ca/index.asp>

FAS Bookshelf Inc.

<http://www.fasbookshelf.com>

University of Washington Fetal Alcohol and Drug Unit

<http://depts.washington.edu/fadu/>

Le Syndrome D'alcoolisation Foetale

French language FASD site.

<http://www.safera.qc.ca>

Alcohol, Other Drugs and Pregnancy

Site maintained by the Department of Human Services, Victoria, Australia.

<http://www.adf.org.au/adp/index.html>

BC and Canadian Resources

BC Government Legislation, Services & Resources

Adult Guardianship Legislation in BC

British Columbia's Adult Guardianship Legislation

<http://www.trustee.bc.ca>

British Columbia Representation Agreement Act

RSBC 1996 Chapter 405. Amended 1999, 2000, 2001.

<http://www.trustee.bc.ca/RAA.pdf>

Service Delivery and Resources

Community Living BC (CLBC)

New governance model for delivery of community living services to people with developmental disabilities in BC.

<http://www.communitylivingbc.ca>

BC Ministry of Children and Family Development

Services for British Columbia children and youth with special needs.

http://www.mcf.gov.bc.ca/spec_needs/index.htm

The Ministry's Autism Resource Directory

http://www.mcf.gov.bc.ca/autism/pdf/autism_directory2002.pdf

BC Ministry of Health

Mental Health and Addictions

<http://www.healthservices.gov.bc.ca/mhd/>

Every Door is the Right Door

A British Columbia Planning Framework to Address Problematic Substance Use and Addiction.

http://www.healthservices.gov.bc.ca/mhd/pdf/framework_for_substance_use_and_addiction.pdf

BC Partners for Mental Health and Addictions Information

The BC Partners for Mental Health and Addictions Information (BC Partners) is a partnership among seven provincial mental health and addiction agencies aimed at building mental health literacy among British Columbians. The BC Partner organizations comprise:

- Anxiety Disorders Association of BC (ADABC)
- Awareness and Networking around Disordered Eating (ANAD)
- BC Schizophrenia Society (BCSS)
- Canadian Mental Health Association - BC Division (CMHA)
- Kaiser Foundation (Kaiser)
- Mood Disorders Association of BC (MDA)

Planning Guidelines for:

Mental Health and Addictions Services for Children, Youth and Adults with Developmental Disability

- The Force Society for Kids Mental Health of BC

This initiative is directed through the provincial Mental Health and Addictions Information Plan for Mental Health Literacy (available on the Ministry of Health website, at <http://www.healthservices.gov.bc.ca/mhd/pdf/infoplan.pdf>) and managed by the Provincial Health Services Authority (PHSA), with the objective of establishing and maintaining a communication infrastructure to provide evidenced-based information for:

- people with mental disorders and substance use disorders and their families
- mental health and addictions professionals, and
- other sectors of the BC population

In 2002, the BC Partners developed a website, <http://www.heretohelp.bc.ca>, with the aim of improving the mental health literacy of British Columbians, and allowing individuals to gain access to, understand, and use information in ways that promote and maintain good mental health. It also promotes the knowledge, beliefs, and abilities that enable recognition, management, and prevention of mental health and substance use problems.

The website is a warehouse of evidenced-based mental health and addictions information, including:

- fact sheets on mental health and addictions issues
- self-management tools on mental illness, depression, and anxiety disorders
- state-of-the-knowledge reports
- wellness modules, and
- *visions*, a nationally-award-winning journal that provides an in-depth examination of mental health and addictions issues and policies.

BC Ministry of Health and BC Association for Community Living

Right to Health Care: Securing Health Care Access for Persons with Developmental Disabilities, (2000).
British Columbia Association for Community Living and the BC Ministry of Health.

This document, primarily for clinicians, suggests ways for family and community members to work in partnership with physicians and hospitals to gain equitable access to health care for people with developmental disabilities.

Ordering BC Government Publications

All British Columbia government publications and legislation are available through the Queen's Printer, at:

Crown Publications Inc.
521 Fort Street, Victoria, BC. V8W 1E7
Phone: 1-250-386-4636
Fax 1-250-386-0221
<http://www.publications.gov.bc.ca>

Additional BC and Canadian Resources

In Canada, and in BC, numerous other organizations provide support to families, professionals, health care providers, and researchers through publications, advocacy, and various educational activities. Some of these organizations are listed below.

BC

Advocate for Service Quality in British Columbia

Phone: 1-604-775-1238

http://www.mcf.gov.bc.ca/getting_help/advocate_service_quality.htm

This organization assists adults with developmental disabilities and their families to obtain high- quality service from the Ministry for Children and Family Development, from other ministries, and from service agencies in the community.

Autism Society of British Columbia

<http://www.autismbc.ca/>

BC Association for Community Living (BCACL)

<http://www.bcacl.org/>

BC Aboriginal Network on Disability Society

Phone: (Victoria): 381-7303 Phone (toll-free): 1-888-815-5511

<http://www.bcands.bc.ca>

BCANDS provides a variety of support services and resources to help BC's aboriginal people with disabilities, and others associated with the disabled.

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BC Coalition of People with Disabilities

<http://www.bccpd.bc.ca>

BC Family Network (BC Federation of Families Society)

<http://www.bcfamilynet.org>

BC Schizophrenia Society

Early Psychosis Intervention (EPI) information.

http://www.bcss.org/information_centre/schizophrenia/early_intervention.html

<http://www.psychosissucks.ca/epi/>

Community Living BC (CLBC)

New governance model for delivery of community living services to people with developmental disabilities in BC.

<http://www.communitylivingbc.ca>

Developmental Disabilities Association, BC (DDA)

<http://www.develop.bc.ca/>

Family Support Institute, BC

<http://familysupportbc.com/index.html>

Institute of Health Promotion and Research, University of British Columbia

<http://www.ihpr.ubc.ca>

Canada

Canadian Association for Research and Education in Intellectual Disability/

Association Canadienne pour la Recherche et L'Enseignement en Deficiance Intellectuelle (CARE-ID/ACREDI)

<http://www.care-id.com/>

Developmental Consulting Program (DCP)

Queens University, Kingston, Ontario

<http://meds.queensu.ca/medicine/comhepi/research/dcp.htm>

Down Syndrome Research Foundation

<http://dsrf.org/>

Gentle Teaching

<http://www.gentleteaching.com/>

J.P. Das Developmental Disabilities Centre, University of Alberta

<http://www.ualberta.ca/~jpdasddc/index.html>

Microboards

<http://www.microboard.org/>

NADD Ontario

<http://www.dualdiagnosisontario.org/>

Ontario Association on Developmental Disability (OADD)

<http://oadd.icomm.ca/>

Planned Lifetime Advocacy Network (PLAN)

<http://www.plan.ca>

University of Western Ontario Developmental Disabilities Division

<http://www.psychiatry.med.uwo.ca/ddp/>

Self-Advocate Organizations

BC People First

<http://www.bcpf.bc.ca/>

SelfAdvocateNet

<http://www.selfadvocatenet.com/>

USA, Europe, and International

Government Publications

Closing the gap: A national blueprint to improve the health of persons with mental retardation. (2002). Report to the Surgeon General's Conference on Health Disparities and Mental Retardation. February 2001. Washington, DC: US Public Health Service:
<http://www.nichd.nih.gov/publications/pubs/closingthegap/index.htm>

Emotional and behavioural health in persons with mental retardation/developmental disabilities: Research challenges and opportunities. (2001, Nov 29 - Dec 1). Workshop Executive Summary. Rockville, MD: National Institute of Neurological Disorders and Stroke.
http://www.ninds.nih.gov/news_and_events/proceedings/Emotional_Behavioral_Health_2001.htm

Review of Access to Mental Health Services for People with Intellectual Disabilities. National Disability Authority, Republic of Ireland.
http://www.nda.ie/_80256F4F005C7F9E.nsf/0/815EB07591494D9D80256F62005E6964?Open&Highlight=2,review.of.access.to.mental.health.services

Organizations in the UK have provided extensive web-based materials, as well as many published plain-language documents addressing the needs of “carers” in relationship to this population. See for example:

Mental health in mental retardation: The ABC for mental health, primary care, and other professionals. Bouras et al. (1999). <http://www.wpanet.org/sectorial/mhinretard1.html>

Planning Guidelines for:

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Valuing People: A new strategy for learning disability for the 21st Century. (2001). CM5086. London: Department of Health. <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>

Government Initiatives

Florida 2010

<http://www.doh.state.fl.us/family/childhealth/childreport/prefix/toc.html>

This organization's goal for children and youth observes that: "Young children with disabilities and conditions which place them at risk for developmental delays are at greater risk of child abuse, and their families are at greater risk for divorce and suicide. While raising young children is challenging for anyone, families with an infant who has special health care needs often feel overwhelmed, frightened, a personal failure, and helpless. They are often unable to find supports such as pre-school or child care to allow them time to go to school, work or even to go shopping. Early intervention can help families learn to cope and take charge, as the most important partner in the child's developmental intervention plan."

POMONA Project

Funded by the European Union Health Monitoring Unit, this project developed a set of health indicators for people with intellectual disabilities. (2002-2004). <http://www.pomonaproject.org/report.php>

International Organizations

National Association for the Dually Diagnosed (NADD)

An organization for people with intellectual disability and mental health needs.

132 Fair Street, Kingston, NY, USA

<http://www.thenadd.org>

The European Association for Mental Health in Mental Retardation

Secretariat: Barbara Starczewski

v. Bodelschwingsche Anstalten Bethel

Maraweg 9, D-33617 Bielefeld/ Germany

tel: +49 (0) 521-144 26 13

fax: +49 (0) 521-144 34 67

email: drmseidel@t-online.de

The International Association for the Scientific Study of Intellectual Disabilities

<http://www.iassid.org/>

The Society for the Study of Behavioural Phenotypes

<http://www.ssbp.co.uk/files/about.htm>

Other

Training Resources

Certificate Program: Habilitative Mental Health for Persons with Developmental Disabilities

Brock University, St. Catharines, Ontario, Canada

In association with Niagara University, Lewiston, NY, USA, and the NADD

<http://www.thenadd.org>

College of Health Disciplines, University of British Columbia

<http://www.health-disciplines.ubc.ca>

The College is a unique and innovative affiliation of seven faculties: Agricultural Sciences, Applied Science, Arts, Dentistry, Education, Medicine, and Pharmaceutical Sciences. Each of these faculties represents either a health discipline or is academic home to one (or more) health or human service schools or departments. The College's mandate is to help health and human service practitioners work together for better health by leading inter-professional education for research. On behalf of its affiliated faculties, the College manages a number of inter-professional courses and works closely with community partners.

Levels of Practice for Supporting Individuals with Dual Diagnosis (PDF only)

http://www.camh.net/Care_Treatment/Program_Descriptions/Mental_Health_Programs/Dual_Diagnosis/dual_diagnosis_resources_pros.html

The Training and Education Work Group of the Dual Diagnosis Implementation Committee of Toronto published this report in 2003. With the staff support of Jenny Carver, a cross-sector multidisciplinary group representing developmental, mental health, colleges and university sectors developed this document to address attitudes, knowledge and skill requirements for the Generalist, the Advanced Generalist, and the Specialist working in the field of dual diagnosis (intellectual disabilities and mental health needs.) It provides a common reference point for practitioners who want to develop their capacity; for training and education programs/courses to develop curriculum; for employers to plan staff development initiatives; and as an advocacy tool to enhance system capacity through the development of formal education programs and standards of professional practice.

Generalist Practice Level Knowledge & Skills Self-Assessment Form

Published in 2004 by the Training and Education Work Group of the Dual Diagnosis Implementation Committee of Toronto, this tool can be used by providers across sectors to evaluate their skills. The tool was piloted by the developmental and mental health sectors. It has been found to be useful for personal self-assessment, group assessment, and/or to support pre-planning for workshops and training programs. The Dual Diagnosis Program at the Centre for Addiction and Mental Health will also compile the results tool for your local group. Contact susan_morris@camh.net

Training Publications

McCreary, B. C., Peppin, P., & Stanton, B. (2001). *Catalysts for university education in developmental disabilities*. Kingston, ON: Developmental Consulting Program. Queens University.

<http://meds.queensu.ca/medicine/comhepi/research/dcp.htm>

Planning Guidelines for:

Mental Health and Addiction Services for Children, Youth and Adults with Developmental Disability

This unique and broad-based reference is a result of a collaborative project of faculty and staff in the Developmental Consulting Program at Queen's University. Part I includes the contributions of a two-day symposium of educators and researchers interested in all aspects of developmental disability. Part II presents a collection of chapters written by members of the Division of Developmental Disabilities in the Department of Psychiatry at Queen's and includes chapters on:

- developmental neuropsychiatry,
- paediatrics and child health care,
- social work,
- clinical psychology,
- neuropsychiatric genetics,
- epidemiology and health promotion,
- legal understanding in medical and social service environments,
- ethical aspects of treatment and research,
- family medicine, and
- evolution of developmental disability policy in Ontario.

The appendices contain action plans to address gaps in the education of professionals in the field of Developmental Disability.

Griffiths, D. M., Stravarakaki, C., & Summers, J., (Eds.). (2002). *Dual diagnosis: An introduction to the mental health needs of persons with developmental disabilities*. Sudbury, ON: Habilitative Mental Health Resource Network. (CD-ROM also available.) Available from: Plaza 69, Postal Outlet, 1935 Paris Street, Box 21020, Sudbury, ON P3E 6G6. ISBN 0-9688694-0-8.

This is a comprehensive and accessible text designed as a “train the trainers” guide. It was developed as a collaboration of 34 teachers/clinicians working with persons with developmental disabilities and mental health needs. The book can be ordered on its own for general use, but trainers and educators receive the opportunity to order an accompanying CD-ROM when the book is purchased. The CD-ROM can be used in presentations. The opening chapter gives an overview of the book, explains how to use it effectively, and provides a unique readers’ guide to the chapters. The audience for the training derived from this book encompasses family, direct care staff, and personnel who work in more clinical and consultative roles. Each chapter begins with learning objectives, contains case examples, and concludes with a “do you know” section at the end, all of which serve to reinforce the main learning points. This book is intended to be a resource, providing background and theoretical framework as well as practical assistance. A curriculum could be developed from this book for college and university courses, as well as for focused workshops for families and direct care staff on particular aspects of the mental health needs of persons with developmental disabilities.

Legal Resources

Law Courts Education Society of BC

This organization has developed a training program to help justice system professionals support persons with developmental disabilities who come into contact with the legal system, as victims or offenders.

<http://www.lawcourtsed.ca/index.cfm?call=0680732c&mnid=307&hl=2&act=main>

BCACL Criminal Justice Project

BCACL project and resources for people with developmental disabilities, families and caregivers.

www.bcacl.org/issues/criminaljustice/index.shtml

<http://www.justiceforall.ca/>

Conry, J. and Fast, D. K. (2000). *Fetal Alcohol Syndrome and the criminal justice system*. Vancouver, BC: British Columbia Fetal Alcohol Syndrome Resource Society and the Law Foundation of British Columbia. ISBN 0-9693767-2-3.

Appendix B: Psychotropic Drug Therapy Guidelines for the Treatment of People with Developmental Disabilities

1. The decision to prescribe psychotropic medication should follow a comprehensive assessment of an individual's emotional and behavioural disturbance.
2. Proper consideration should be given to the issue of informed consent, particularly with respect to BC's consent legislation (see <http://www.trustee.bc.ca>).
3. Treatment with psychotropic drugs should be an integrated part of other concurrent treatments.
4. Integrating psychotropic medication with other modalities requires good interdisciplinary communication.
5. The precise symptoms for which the psychotropic medication is being prescribed should be stated.
6. There should be some rationale to suggest that the drugs to be prescribed are likely to be useful for the target symptoms.
7. One needs to establish some method for reliably and validly documenting changes in the target symptoms during the course of treatment.
8. This record should demonstrate that target symptoms have had a positive response to the medication before the drug is continued.
9. Where the initially prescribed dose has failed to produce improvements, increases in dosage should not continue beyond a predetermined maximum level.
10. When target symptoms have been reduced or absent for a reasonable period, then an attempt should be made to reduce the dose being administered.

Start Low, Go Slow

As a general principle, start with the lowest dose possible and increase slowly.

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11. When a psychotropic medication is withdrawn, a proper withdrawal regime should be designed.
12. Because of the presence of organic dysfunction, the response to psychotropic drugs is often relatively idiosyncratic.
13. Because of the often idiosyncratic response to psychotropic medication, its administration should be regarded to some extent as a therapeutic trial.
14. As with any other individual, general principles of pharmacology need to be observed, including issues of compliance, drug absorption and excretion, drug interactions, and side effects.²⁹

²⁹ *The guidelines in the list above are from Dr. Stewart Einfeld, Department of Psychiatry, University of Sydney, The Children's Hospital, Camperdown, NSW 2050 Australia- Aust.NZ Journal of Developmental Disability 1990:16:71-73*

Appendix C: Dual Diagnosis Mental Health Case Examples

1. Education and Training of Staff Decreases Client Aggression

A 50-year-old man with moderate developmental disability living in a 24-hour staffed group home was referred because of the home's difficulty managing his frequent aggressive outbursts. Interventions initiated by the specialized developmental disability mental health team included minor medication dosage adjustments and staff in-service sessions and education regarding bipolar illness provided at the group home site. Behaviour management plans and accompanying documentation protocols were initiated. These interventions have been effective in decreasing the frequency and severity of this man's aggressiveness.

2. Aggressive Behaviour in a Medically Fragile Client with Significant Concurrent Medical Problems and no Suitable Treatment Milieu

A 10-year-old boy with a developmental disability had numerous surgeries due to congenital heart disease, associated hemiplegia, and seizure disorder. Concomitant severe aggression to others was the main identified problem, along with self-injurious behaviour, hyperactivity, short attention span, sleep disturbance, and autistic features. He had access to behavioural therapy and respite from the family home, and a history of being unresponsive to or developing side effects from psychoactive medication trials. He was assessed by two psychiatrists, who noted that "he doesn't fit into any of the settings we have. His medical problems mean that he really couldn't fit into the ward programs." Three weeks later, he had an emergency admission to a child and adolescent psychiatric emergency unit, with aggression stated as the reason for the admission. This was followed by two subsequent admissions to an adolescent ward. This child required longer admission in a specialized unit, but no such unit was available. The treatment team needed to assess medication response and the child's behaviour away from the family home. His family needed more intensive assistance with behaviour management.

3. Misunderstanding the Function of Behaviour

A young woman with mild developmental disability has been increasingly withdrawn. She lives in a small group home and spends most of the day in her room. She is in danger of losing her job due to frequent absences. In the morning, the group home staff wake her and prompt her to get ready for

work. She refuses and uses some profanities. A little time passes and, concerned that she will be late again, a preferred staff member repeats the prompts to be up and get ready. The young woman screams at her and hits the staff member. The staff member retreats, frustrated and angry, after the assault.

The staff feel the client is being resistive and aggressive. They meet and plan behavioural interventions using a mixture of incentives (access to preferred activities) and punishments (loss of preferred activities) to get her to go to work and be more involved in social activities. The intervention is unsuccessful.

The young woman becomes increasingly withdrawn and aggressive. She refuses food and is eventually hospitalized. This young woman had an undiagnosed depressive illness, and her depressive symptoms reduced the reinforcing value of work (pay check) and social activities (interaction). The prompts to go to work or engage in activities are perceived as aversive, which triggers refusals and aggression. Lack of understanding of the relationship between depressive symptoms and the young woman's behaviour made the intervention fail and the situation worse (from Baker & Blumberg, 2006).

4. *Effect of Under-Treated/Undiagnosed Physical Illness on Mental Health*

A young woman in her mid-thirties with Down Syndrome and a moderate developmental disability has been living independently with support services in her own apartment for several years. A referral was made to a community psychiatrist familiar with developmental disabilities for re-assessment of depression, possible early onset dementia, suicidal thinking, and failure to respond to treatment with a Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant.

This young woman had gained considerable weight and gave a history of sleeping on four pillows, fatigue, and having many symptoms of depression. Recommendations included overnight fingertip oximetry to check for sleep apnea (test was positive for significant sleep apnea); a re-check of thyroid function (was on a low dose of thyroid replacement hormone); and fasting blood sugar for diabetes (normal). Her thyroid function was abnormal. It indicated that her dose of thyroid replacement was too low and it was subsequently increased.

A new family doctor was found who was willing to support the recommendations and work with the community team. Treatment for sleep apnea was initiated with a continuous positive airway pressure (CPAP) machine. However, checks for compliance showed that the machine was used sporadically. The social worker and care team suggested that the young woman consider a change in living situation and move in with an experienced caregiver. The family supported this move. This new living situation with increased support has been positive and use of the CPAP has been consistent, with resulting increase in energy and improvement in thinking and in mood. Weight loss has been possible with persistent effort and pride by this young woman.

5. Aggression as Referral Reason Highlighting Importance of Knowing History and Meaning of Specific Challenging Behaviour

A man, aged thirty-five, with a moderate developmental disability, was living in small group home when he was referred because of agitation, anger outbursts, and mood lability. The etiology of his disability is vague. His mother may have had Rubella during pregnancy. This individual had a past history of seizures but had been seizure free for many years. He had been institutionalized in childhood due to the family situation and his level of aggression in the home. Previous medication history included chlorpromazine, valproic acid, and carbamazepine. At the time of referral, the medication was carbamazepine with a blood level in the therapeutic range indicating that prior higher levels of medication may have been in the toxic range.

This individual has a family history of bipolar disorder, considerable family trauma, and was a victim of sexual assault during institutionalization. Early trauma and attachment difficulties were evident, in addition to ongoing trauma, resulting in difficulties with modulating emotions. However, mood symptoms were not felt to be currently present (and may have been decreased by treatment with carbamazepine as a mood stabilizer).

Symptoms of Posttraumatic Stress Disorder were present. A review of outbursts suggested that they served as methods of avoidance or intimidation when the individual became anxious. Recommendations included continuation of carbamazepine for modulation of aggression and mood; addition of a low dose of an antidepressant for anxiety symptoms; art therapy for past history of sexual abuse and trauma; and detailed behavioural strategies to provide him with safe alternatives to “escape” from anxiety-provoking situations.

6. Self-Injurious Behaviour, Anxiety and Family Dynamics

A young woman with Prader-Willi Syndrome and a mild developmental disability was living at home and had a long-standing pattern of intermittent skin picking and gouging, especially of arms and legs, often resulting in secondary infections and antibiotic treatment. She also liked to collect objects, which were typically not of any real value but were often sharp (e.g. paper clips). When anxious or stressed, she would gouge her skin with these found objects, often when she was alone in her bedroom. Negotiating with her to remove the objects from her pockets voluntarily when returning home had been less than successful for many months, and often resulted in both her and her mother feeling very upset.

Psychiatric assessment brought a suggestion for a trial of a Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant for anxiety symptoms and “sticky” perseverative thinking. As well, a referral to a behavioural consultant resulted in her parents realizing that their concern over their daughter’s frequent infections and self-injury had turned into a power struggle, and had resulted in increased restrictions on her activities. A simple script was developed around the pocket emptying and her parents began to increase the number of choices available to their daughter. Over a couple of months, this young woman’s anxiety and perseveration decreased, and she was more willing to empty her pockets when returning home. The request to have her empty her pockets was now made in a low-key way and with a neutral voice. A decrease in incidents of skin picking and infections

followed. Both the Selective Serotonin Reuptake Inhibitor (SSRI) antidepressant and the behavioural strategies were needed.

7. Diagnostic Overshadowing: Cerebral Palsy and Developmental Disability “overshadow” Bipolar Disorder

A 16-year-old boy with cerebral palsy and a moderate developmental disability was referred due to concerns about his periods of sleeplessness and coinciding increases in “obsessiveness,” intrusiveness, and agitation. He would go for up to three days without sleeping, and these episodes occurred three or four times a year, for a week or two at a time. He was diagnosed with Bipolar Disorder, treated with carbamazepine for mood stabilization, and showed considerable improvement. His parents expressed frustration that, while a mental health disorder was recognized immediately by a specialized mental health service, this had not been considered in previous generic medical treatment.

8. Apparent Gender Issues Actually Obsessive Component of Asperger’s Disorder

A man in his early twenties with borderline intellectual functioning had been experiencing numerous symptoms of anxiety and obsessional thinking. He was well known to various mental health service providers due to his efforts to find support for gender reassignment. After considerable education and assessment, gender issues were determined to be related to obsessive thinking common to those with Asperger’s disorder, rather than actual gender disorder. Community service providers were open to gender issues being a causal factor, but with considerable expertise the difference was delineated between true gender issues and symptoms of a pervasive developmental disorder (PDD). Client functioning improved with redirection of gender concerns and emphasis on vocational and social functioning.

9. Co-morbid Anxiety and Obsessive-Compulsive Symptoms Diagnosed in a Young Teen with Autism and Attention Deficit Hyperactivity Disorder (ADHD)

A 14-year-old boy with high-functioning Autism was referred to a specialized mental health and addiction team for assessment regarding a significant increase in hostility and aggression over the previous six-month period. This young man had been treated with Ritalin for several years, for symptoms consistent with Attention Deficit Hyperactivity Disorder (ADHD). Team assessment found that the young teen had multiple symptoms of anxiety and obsessive thinking, which were co-morbid and untreated. A trial with a Selective Serotonin Reuptake Inhibitor (SSRI), citalopram, was initiated to address these previously undiagnosed, untreated symptoms.

10. Diagnostic Overshadowing

Caregivers referred a man in his forties, requesting psychiatric and behavioural assessment. He had past diagnoses of cerebral palsy and developmental disability. No formal assessments were on file, but he appeared to be functioning with a mild to moderate level of delay. Concerns were expressed about the man's tendency to "laugh" and make noises, primarily while eating, but also at other times. He had also had a couple of incidents of angry outbursts. A review of old records revealed that this man had had a long history of institutionalization and numerous losses. File notes confirmed the same "behaviour" of laughing and noises for the past twenty-five years. One symptom of cerebral palsy can be involuntary/labile noises that increase with stress. The outbursts occurred after the man's limited privileges were curtailed due to his noise-making. The man reported an increase in his happiness after caregivers were provided with education about his history and about cerebral palsy, and after an eventual move to another home.

Appendix D: Glossary of Definitions and Acronyms

Key Developmental Disability Concepts & Definitions (from Bouras, 2003)

Learning disabilities

This term has been used in the UK in recent years instead of the internationally used term “mental retardation,” as defined in the DSM-IV-TR and ICD-10 classification systems. The diagnosis of learning disabilities requires a significantly below average level of intellectual functioning, such as an IQ of below 70 on a standardized test; a significant impairment of adaptive functioning; and onset in childhood. The term therefore refers to a group of heterogeneous conditions, with a varying range of complex needs, and not to a single condition.

Mental/psychiatric disorder

This term is used in this document to mean any diagnosis included in the ICD-10, DSM-IV-TR, or DC-LD³⁰ international classification systems.

Challenging behaviour

Emerson and Hatton (1995) define challenging behaviour as culturally abnormal behaviour(s) of such intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in jeopardy; or behaviour which is likely to seriously limit use of services or result in the person being denied access to ordinary community facilities.

It is a social construct that is not included in any diagnostic classification system, and which implies that the behaviour of a person with learning disabilities challenges services to rise to meet his/her needs. While people with learning disabilities may have challenging behaviour without having an underlying psychiatric diagnosis, for many individuals these may co-exist. Challenging behaviour may be related to environmental factors alone or to an underlying psychiatric or physical disorder, or to a

³⁰ For more on DC-LD, see Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD). London: Gaskell, Royal Colleges of Psychiatrists, 2001. Distributed in North America by the American Psychiatric Press, <http://www.psych.org>.

combination of any two or all three factors. People with challenging behaviour (in the absence of a mental disorder) are most likely to have moderate to severe learning disabilities. Challenging behaviour is contributed to by certain circumstances, including poor environment, communication difficulties, challenging behaviours that are a learned response, and inappropriate staff (carer) responses to their behaviour.

Mental health problem

This term is frequently used in services for persons with learning disorders. Mental health problems are operationally defined as any mental disorders included in any of the classification systems, or challenging behaviour that requires psychiatric mental health interventions such as assessment, treatment with medication, etc. (Bouras et al., 2003)

Other Definitions

Anhedonia

Reduced or complete inability to feel pleasure from activities that usually produce happiness.

AXIS II

The *Diagnostic and Statistical Manual of Mental Disorders*, presently in its fourth revised (IV-TR, 2000) edition, systemizes psychiatric diagnosis in five axes. Axis II addresses underlying pervasive or personality conditions, as well as mental retardation.

Behavioural overshadowing

The tendency to attribute all problems to the person's behaviour.

Behavioural phenotype

A pattern of behaviour that is reliably identified in groups of children and adults with known genetic or other syndromes and is not learned.

Cohort

A well-defined group of people who have had a common experience. For example, a group of people born during a particular period or year is called a birth cohort.

Collaborative care

Different practitioners working together with the patient in order to provide the best possible care.

Co-morbid

The presence of more than one disorder. An example would be an individual having both ADHD and depression.

Counterfeit deviance

Situations in which lack of sexual knowledge is a primary reason for inappropriate sexual behaviour in individuals with developmental disabilities.

Diagnostic equivalents	Behavioural symptoms that may indicate the presence of a psychiatric disorder—for example, observed irritability instead of self-reported depressed mood in depression.
Diagnostic overshadowing	The tendency to attribute all problems to a person's intellectual disabilities - e.g. failing to identify, and therefore to treat, a person's superimposed depressive episode or anxiety disorder.
Distance technologies	Use of telehealth, video conferencing, or other technologies to provide clinical support across distances.
DSM-IV-TR classification system	The <i>Diagnostic and Statistical Manual of Mental Disorders</i> , presently in its fourth revised (IV-TR, 2000) edition, systemizes psychiatric and physical diagnoses, psychosocial stressors, and adaptive functioning in five axes.
Folie a deux	Literally “a madness shared by two.” A rare psychiatric syndrome in which a symptom of psychosis (particularly a paranoid or delusional belief) is transmitted from one individual to another, and is believed by both.
Fregoli delusion / Fregoli syndrome	A rare disorder in which a person holds a delusional belief that different people are in fact a single person who changes appearance or is in disguise.
Functional assessment	An assessment that addresses the major functional areas, including behaviour, communication, and social/community functioning.
Hemiplegia	Full or partial paralysis of one side of the body due to disease, trauma, or stroke.
Horizontal service linkage	Horizontal linkages allow interaction between groups freely and directly without having to operate through rigid vertical channels of command. Linkages are based on commonalities and complementarities and allow groups to combine knowledge, skills and expertise. They are non-hierarchical and non-linear, and relate the activities of different groups, agencies or departments that have shared concerns and serve to establish coordination and cooperation—so their collective efforts work together toward the successful implementation of strategies and solutions. In contrast, vertical linkages are those tying together an organization “from top to bottom”: from corporate, to division, to department.
Hypochondriasis	Preoccupation with fear that one has a serious medical illness even though a medical evaluation has ruled out such an illness.

Labile	Changing quickly. Most often refers to unstable emotions or could refer to an unstable blood pressure or blood sugar level.
Obsessional slowness	An uncommon but severely disabling variant of obsessive-compulsive disorder.
Oximetry	A method of measuring the oxygen content of blood.
Perseverative thinking	Inability to “see” anything else, or to move on to other ideas.
Pervasive Developmental Disorder	A generic term referring to a group of disorders that are characterized by: impairments in social interaction; impairment in verbal and non-verbal communication; and a restrictive, stereotypic pattern of behaviours. There is considerable variability in symptoms among individuals with PDD and considerable variability in the severity of these symptoms. A variety of disorders fall under this category, including Autism, Asperger's Syndrome, Rett's Syndrome, etc.
Shared care	A process that promotes collaboration between providers from different services or disciplines who share responsibility for the care that an individual receives. In this approach, mental health and addiction staff and primary care providers work together as part of a well co-ordinated mental health and addictions health care delivery system that spans both primary and specialized care. (For example, joint appointment between mental health and addiction centres and family physicians holding joint clinic and educational rounds.)
Step-down capacity	Moving from a higher level of care, with intensive services, to a lower level of care, with less intensive services.
Teratogenic	A chemical or environmental agent that causes mal-development of the fetus.
Trinucleotide repeat	Trinucleotide repeat disorders (also known as trinucleotide repeat expansion disorders or expansion disorders) are due to stretches of DNA in a gene that contain the same trinucleotide sequence repeated many times. These repeats are a subset of unstable microsatellite repeats that occur throughout all genomic (gene) sequences and, if the number of repeats reaches a certain level, the effects can cause disruption in gene sequencing, protein formation, and enzyme function that may result in physical, neurological, and mental disabilities. Fragile X Syndrome is an example.

Velocardiofacial syndrome

A disorder that has been associated with over thirty different features³¹. The name velocardiofacial syndrome comes from the Latin words “velum” meaning palate, “cardia” meaning heart, and “facies” having to do with the face. The most common features are cleft palate (opening in the roof of the mouth), heart defects, characteristic facial appearance, minor learning problems, and speech and feeding problems. Not all of these identifying features are found in each child who is born with VCFS. VCFS is associated with increased incidence of bipolar disorder and schizophrenia. Also known as 22q11.2 deletion or DiGeorge Syndrome.

Velopharyngeal

Referring to the soft palate and pharynx region.

Acronyms

AAMR	American Association on Mental Retardation
ABA	Applied Behavioural Analysis
ADL	Activities of Daily Living
ALC	Alternative levels of care
ASD	Autism Spectrum Disorder
ACT	Assertive Community Treatment
BCAAN	BC Autism Assessment Network
BCCH	BC Children’s Hospital
CAPE	Children’s Adolescent Psychiatric Emergency Unit
CDBC	Complex Developmental Behavioural Conditions
CIHI	Canadian Institute for Health Information
CLBC	Community Living BC
CYMH	Child and Youth Mental Health
DC	Diagnostic Criteria

³¹ A disease or disorder that has more than one identifying feature or symptom is a syndrome.

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DD	Developmental Disability
DS	Down Syndrome
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders IV-TR
ECD	Early Child Development
ECT	Electroconvulsive Therapy
EICO	Early Intervention Community Outreach
EPI	Early Psychosis Intervention
FASD	Fetal Alcohol Spectrum Disorder
FTE	Full Time Equivalent
FHA	Fraser Health Authority
FPH	Forensic Psychiatric Hospital
HCP	Health care provider
HSCL	Health Services for Community Living
ID	Intellectual Disability
IF	Individualized Funding
IHA	Interior Health Authority
LD	Learning Disability (UK equivalent to Developmental Disability)
MCFD	Ministry of Children and Family Development
MHST	Mental Health Support Teams
MOU	Memorandum of Understanding
MR	Mental Retardation
MR-SD	Mental Retardation And Substance Disorder
NAC	National Advisory Committee (of Health Canada for FASD)
PAC	Provincial Assessment Centre (formerly Willow Clinic)

PHSA	Provincial Health Services Authority
PTSD	Posttraumatic Stress Disorder
RVH	Riverview Hospital
SDM	Substitute decision maker
SET-BC	Special Education Technology - British Columbia
SIS	Supports Intensity Scale
SSRI	Selective Serotonin Reuptake Inhibitor
START	Systemic, Therapeutic, Assessments, Respite and Treatment
TSDM	Temporary Substitute decision maker
VCFS	Velocardiofacial Syndrome

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