

Co-Occurring Developmental Disabilities and Mental Health Problems

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Introduction to dual diagnosis



Outline

- How common is dual diagnosis?
- The relationship between developmental disability and mental health problems
- The impact of dual diagnosis
- An introduction to treatment

Introduction to dual diagnosis

ONE PARENT'S PERSPECTIVE

In grades 10–11 the education changes: it's not just learning principles and rules; it is applying information in problem solving. Abstracting information was hard and he couldn't solve ambiguous problems, so he started to fail a lot and couldn't continue his education. Inexperienced teachers added to the problem, and he had prolonged hardship at that time, and he was just taking it all in and trying to deal with it himself. He had a lot of bullying at school from peers, who would steal his shorts at basketball, and he would fail the course because kids would bully him. After that, he stopped going to school and we brought him to psychiatrists to get help.

He doesn't accept being disabled; it is hard for him to accept this openly. Because of problems with the abstract, he has a hard time seeing mental disability, only physical disability. We were dealing with a bad psychiatrist who prescribed the wrong medication, which made him worse instead of better. It was terrible for him; it didn't work. Not only did it not work, but there were side-effects; we were inexperienced. He became more agitated, more hyper and more angry. We were inexperienced with medications. . . . Then my son became so angry and violent after the therapist had left that we had to call 911 to get help. But he had the bad experience the first time he was taken to ER. The paramedics came and apprehended him and placed him on a stretcher with restraints.

The term *dual diagnosis* describes a situation where someone has both a *developmental disability* and a mental health problem. A developmental disability involves significant limitations in cognitive and adaptive functioning that originated before the person reached 18 years of age.

Many families share similar experiences to those of the family whose story introduces this chapter. Developmental disabilities and mental health problems are sometimes very hard to tease apart. Family members and treatment professionals often find it difficult to determine whether the behaviour they are looking at is due to an underlying disability or a mental health problem—or both.

HOW COMMON IS DUAL DIAGNOSIS?

People with developmental disabilities are at increased risk for developing mental health problems across the lifespan. Large-scale studies indicate that a child with a developmental disability is six times more likely to have a mental health problem than a person who does not have a developmental disability (Emerson & Hatton, 2007). An adult with a developmental disability is three to four times more likely to develop a psychiatric disorder at some point in their life than a person who does not have a

developmental disability (Cooper et al., 2007). Although estimated rates can change depending on the types of problems included as the “second” diagnosis, it is clear that many people with developmental disabilities develop serious mental health problems.

- Psychotic disorders have been estimated to occur three times more often in adults with developmental disabilities compared to the general population (Cooper et al., 2007; Turner, 1989). However, sometimes when people with developmental disabilities are very distressed, their behaviour can appear psychotic and they may be misdiagnosed as having a psychotic disorder.
- Mood disorders (e.g., major depression, bipolar disorder, dysthymia) are also common. One large study in the United Kingdom reported that mood disorders were three times more common in those with developmental disabilities than the general population (Richards et al., 2001). However, mood problems are less likely to be identified in people who have developmental disabilities.
- Anxiety disorders (e.g., posttraumatic stress disorder, separation anxiety, social phobia, specific phobia, panic disorder, generalized anxiety disorder) are more common in people with developmental disabilities. Their prevalence increases with specific genetic syndromes (Harris, 2006). Like mood problems, anxiety problems are less likely to be diagnosed if a person has a developmental disability.
- Challenging behaviour, sometimes referred to as disruptive or problem behaviour, is defined as behaviour which, because of its intensity, frequency or duration, puts the physical safety of the person or others at risk (Emerson & Emerson, 1987). The overall prevalence of challenging behaviour in adults with developmental disabilities has been estimated at 22.5 per cent (Cooper et al., 2007). Challenging behaviour is often a way of communicating that something is wrong. An underlying psychiatric disorder is one possible cause of this behaviour. It may also be triggered by pain or changes in the person’s environment.

Understanding the terminology

People often have mental health problems that significantly affect their daily lives, but that are not severe or long-lasting enough to meet the criteria for a diagnosis of a psychiatric disorder. In this guide, we will usually use the broader term “mental health problems,” unless we are talking about a specific *Diagnostic and Statistical Manual of Mental Disorders (DSM)*-based diagnosis of a disorder.

Below are terms you will probably hear used in some parts of the developmental service and mental health systems.

The **DSM** is used in North America to diagnose mental health disorders and is organized into major diagnostic classes. Within these diagnostic classes, disorders are further broken down—for example, depressive disorders and bipolar disorders are included in the mood disorders class. For each disorder, the *DSM* lists specific

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criteria for making a diagnosis. The fifth edition of the *DSM* was published in May 2013.

DSM Psychiatric disorders (including *substance use disorders*) are health conditions that are characterized by changes in the way a person usually thinks, feels or behaves (or some combination of the three), associated with distress and/or impaired functioning (American Psychiatric Association, 1994).

Dual diagnosis (in Ontario) is a term reserved for people with a mental health problem and a developmental disability. In the United States, this term “dual diagnosis” means that a person has co-occurring mental health and substance use problems, whereas in Ontario, that is called a “concurrent disorder.”

THE RELATIONSHIP BETWEEN DEVELOPMENTAL DISABILITY AND MENTAL HEALTH PROBLEMS

The relationship between a developmental disability and mental health problems is complex. Mental health problems present in unique ways in people with developmental disabilities. How they present can change over time.

- There are biological, psychological and social elements that make it more likely that a person with a developmental disability will develop a mental health problem.
- How mental health problems look can depend on the developmental disability. It can be difficult to understand the inner experience of a person with a developmental disability because they might have difficulty expressing their thoughts and feelings. This makes using traditional diagnostic tools such as the *DSM* challenging because they depend on a person being able to report about their inner experience.
- It is also hard to make a diagnosis when the behaviour of concern has increased in intensity but is an “old” behaviour, meaning that it has been exhibited by the person for a long time. For example, if a man always pulls his hair to get food, but has begun to pull his hair much harder and more often, and not just for food, does this change mean he has a new mental health problem, or is it just part of the same problem?
- Diagnosing mental health problems in someone with a developmental disability requires information from a number of sources from different settings.

THE IMPACT OF DUAL DIAGNOSIS

According to the National Coalition on Dual Diagnosis (2011), people with a dual diagnosis:

- have complicated medical and psychiatric needs, yet are bounced from one service to another, with many services not understanding or helping them
- can have chronic medical and psychiatric problems because they were not caught earlier when they would have been easier to treat
- can be over-medicated because they are “better managed” that way
- often fall between the cracks, as service agencies feel ill-equipped to provide supports
- can be left without support to help them manage life in the community. As a result, they may come into contact with the law and end up in jail or on forensic units in psychiatric hospitals
- are often denied places in housing services because “their needs are too complicated.” Life on the streets for this extremely vulnerable group exposes them to exploitation and violence
- may have been rejected by their family—or have rejected their family—and are without any support. These are the people who are most vulnerable to homelessness
- lose opportunities to be productive citizens because of system failures. There is also loss of family income and productivity, as family members must care for the person with complex needs
- can have behaviours that are out of control because there is little help—and, families feel, no one cares.

Impact on the family

Dual diagnosis directly affects the person experiencing the disorder, but it also has powerful effects on family members. For example, as problems become more complex, family members are often confused about which problems are causes and which are effects. They are often puzzled and frustrated if their family member continues to have problems even after seeing a mental health professional or getting new medication. According to the National Coalition on Dual Diagnosis (2011):

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

Introduction to dual diagnosis

uncoordinated services can leave families, significant others and caregivers feeling frustrated and drained. Respite care and access to their own support services are inconsistently available (p. 7).

AN INTRODUCTION TO TREATMENT

Detecting developmental disability and mental health problems

Because of the overlap of symptoms between mental health problems and developmental disabilities, it is often difficult to make a firm diagnosis in the early stages. For example, becoming very irritable, often losing one's temper and lashing out at others might be due to frustrations in a person who has trouble communicating because of their disability, or it can signal depression or other mood problems. It is important for clinicians to take a good history of what the person was like before the problems started and ask if there are factors in the person's life that have changed before they can say whether a person has a mental health problem. Mental health professionals are very concerned about behaviours that may have changed for the worse. These are clues to the beginning of a mental health problem.

It is equally important to see if there are physical (i.e., medical) problems that are not being taken care of that might be causing the change in behaviour. It is common for people with developmental disabilities to experience what looks like a mental health problem but is actually a response to an undiagnosed and untreated medical issue. Left untreated, a medical issue can lead to a secondary mental health problem or, at the very least, to serious emotional distress. For example, a person who is chronically constipated and who may not be able to appropriately express the source of their pain or the need for help might exhibit serious challenging behaviours that will only stop once the constipation is addressed.

Where do people find treatment?

In Ontario, responsibility for services for people who have developmental disabilities and mental health problems is split among three ministries.

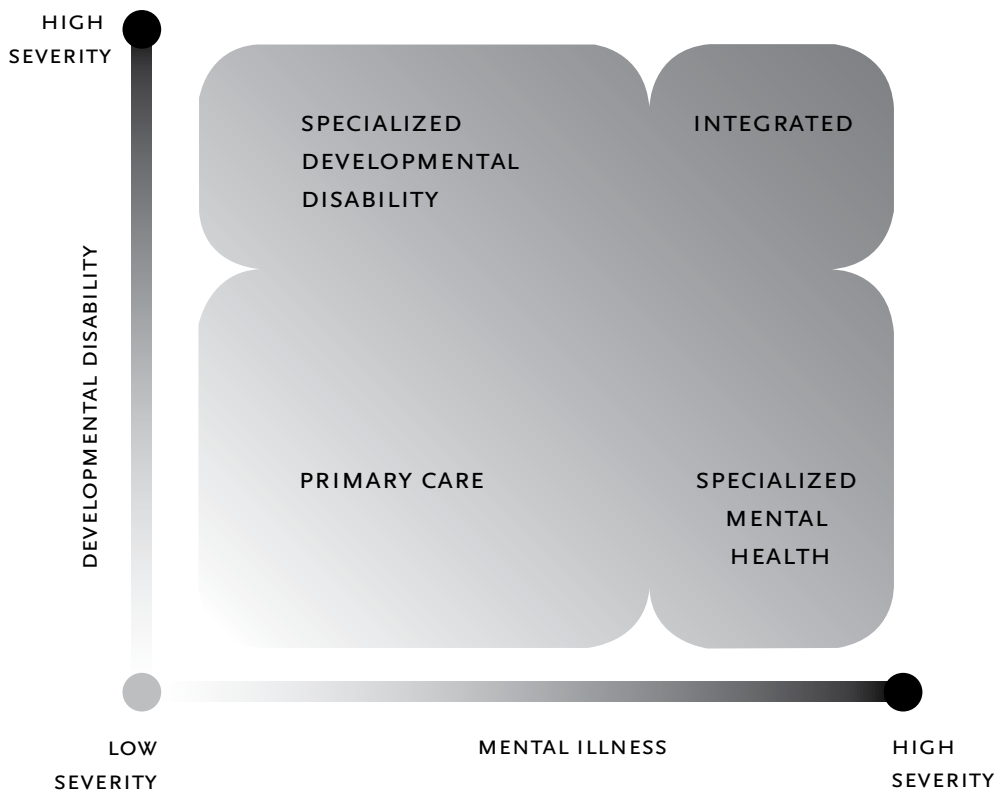
The Ministry of Community and Social Services and the Ministry of Children and Youth Services fund services in the community, often called "the developmental sector." The developmental sector can include in-home and out-of-home respite, employment programs and other day activities and residential services. In July 2011, Ontario introduced centralized access to developmental disability services for people aged 16 and older through [Developmental Services Ontario \(DSO\)](#). There are nine DSO regional offices across Ontario. You can find out more information, including where your local DSO office is located, at www.dsontario.ca.

The Ministry of Health and Long-Term Care funds general health services (e.g., medical assessments and hospital-based services). It also funds the assessment and treatment of mental health problems (e.g., psychiatric emergency treatment, outpatient mental health clinics, acute-stay hospital beds, extended residential care and assertive community outreach teams).

Many people get treatment for mental health problems from family doctors or other primary care services.

A framework (developed in the United States) illustrates where people are most likely to look for treatment. It was originally developed for people who have both a substance use problem and a mental health problem, but it can be adapted for people with developmental disabilities and mental health problems. People may move back and forth among the quadrants at various stages of treatment for mental health problems and may require various amounts of support for their developmental disability, depending on their environment.

Figure 1-1: The Quadrant Framework



Introduction to dual diagnosis

The quadrant framework suggests that when a person has:

- **both a developmental disability and mental health problems of low to moderate severity**, primary health care providers (e.g., family doctors) and community resources are the core resources to draw upon
- **a severe level of developmental disability, with a mental health problem of mild to moderate severity**, specialized developmental disability services are the lead resources, with specialized mental health services providing collaborative care
- **a mental health problem of high severity, with a developmental disability of mild to moderate severity**, specialized mental health services are the lead resources, with developmental disability services providing collaborative care
- **both a developmental disability and mental health problems of high severity**, integrated care by a single, multidisciplinary team is the most effective way to provide continuing care and support.

CO-ORDINATED CARE

According to *Supports and Services for Persons with a Dual Diagnosis: A Resource Manual for York Region Families* (York Support Services Network, 2007):

The fact that two ministries are involved can make it quite complicated to know how to get services and where to begin to look for them. Sometimes people get connected to one sector or the other, but usually not to both. When this happens they will not get the help they need because they are missing what is needed from the other sector. For example, if a person with an intellectual disability has a worker in the developmental sector they might not know the signs for depression and what to do to help. In another situation, a person, diagnosed with schizophrenia, might have a mental health worker from the health sector that is helping them cope with the symptoms of schizophrenia and making sure their medication is right but they might not know what to look for to know if the person also has an intellectual disability. It can be difficult and confusing for everyone involved finding the right kind of help and support. It really works best if there is a special combined approach with both the health and developmental sector and for everyone to work together as a team (p. 12).

Each sector has areas of special knowledge that it can offer. For example, the developmental sector can help with planning, such as where to live and what supports are needed in the community, while the health sector (mental health) can assist in areas such as treatment of mental illness and medication.

In the past, mental health and developmental disability services have not been well connected. They have tended to concentrate on one set of problems and view the other as secondary. However, we know that if problems are not addressed together, they usually get worse, and complications often arise.

Most communities have resources that could provide collaborative programming. In some cases, this already happens. In others, services in both systems need to work together more effectively to provide client-centred care for people with complex needs. We discuss strategies for navigating the treatment system in Chapter 6.

Treatment principles

People who have mental health problems and developmental disabilities are some of the most vulnerable people in our society and in our health care system. Evidence suggests that if we address their problems in more co-ordinated and collaborative ways, people are more likely to get better. This means that instead of getting separate services for each type of difficulty, we take an approach that integrates services.

Dual diagnosis treatment initiatives focus on improved screening and assessment, more specialized programming and co-ordination (by one person or a treatment team) of developmental disability and mental health treatment. Five principles guide how to care for people with dual diagnosis:

1. People with dual diagnosis are people *first*. They have strengths as well as problems.
2. Mental health problems in developmental disability are under-identified but common.
3. Mental health problems in developmental disability are complex but understandable.
4. Mental health problems in developmental disability are challenging but responsive to care.
5. Mental health problems in developmental disability require responses that go beyond *separate* disability and mental health treatment.

For many people, this is a long, complex process. Often family members are the most constant companions in this journey. At points in the journey, the family may be called on to advocate, to support and to act as case managers. In the rest of the guide we offer tools and strategies to help you do this.

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Developmental disability

2

Outline

- What is a developmental disability?
- Why do people have developmental disabilities?

Developmental disability

WHAT IS A DEVELOPMENTAL DISABILITY?

According to Ontario law, developmental disability is an umbrella term for different disabilities that involve significant limitations in cognitive functioning (intellectual capacity to reason, organize plan, make judgments and identify consequences) and adaptive functioning (person's capacity to gain personal independence based on their ability to learn and apply conceptual, social and practical skills in everyday life). These limitations need to originate before the person reaches 18 years of age, are likely life-long in nature and affect areas of major life activity, such as personal care, language skills or learning abilities (*The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* [2008]).

These disabilities can be genetic in origin, like Down syndrome or Fragile X syndrome. They can be caused by illness or injury prenatally or in childhood, like congenital rubella, fetal alcohol syndrome or meningitis, and sometimes the cause is not known, as with autism spectrum disorder. One to three in 100 people in Canada are thought to have a developmental disability.

People with developmental disabilities are nearly always identified by the elementary school years (and often much earlier). Most will have more difficulty problem solving than peers without developmental disabilities and will need support to live independently. The intensity of this support depends on many factors, including their intellectual ability, the things they would like to do, the demands placed on them by society and their stage in life. Every person with a developmental disability has strengths and weaknesses, and supports need to be tailored to their specific needs. Interventions should help them live as independently as possible. A developmental disability is not a disease that requires a cure, but a set of intellectual difficulties that require added support. Three common types of developmental disability are described below: Intellectual disability, autism spectrum disorder and fetal alcohol spectrum disorder.

Intellectual disability

Intellectual disability is a type of developmental disability characterized by significant limitations in both *intellectual functioning and adaptive behaviour*, which covers many everyday social and practical skills. These limitations develop before age 18 (American Association on Intellectual and Developmental Disabilities, 2010).

- Intellectual functioning, also called intelligence, refers to general mental capacity, such as learning, reasoning and problem solving.
- Adaptive behaviour refers to three types of skills:
 - conceptual skills (language and literacy, money, time, number concepts, self-direction)

- social skills (interpersonal, social responsibility, self-esteem, gullibility, social problem solving, following laws)
- practical skills (activities of daily living, occupational skills, health care, travel and transportation, safety, use of money).

In some circles, the severity of a person's intellectual disability is measured by their IQ score level (e.g., mild or severe). Newer ways of understanding disability use the level of support a person needs to fully participate in the community (e.g., intensive supports or intermittent supports).

Autism spectrum disorder

Autism spectrum disorder (*DSM-IV* category pervasive developmental disorder) is an umbrella term for a cluster of difficulties that can vary in severity, but includes socio-communicative deficits (problems with social interaction and social communication) and restricted or rigid behaviours and difficulty adjusting to change. Symptoms may not always be recognized immediately, but are always present from early childhood.

In the *DSM-IV*, Asperger's disorder is a subcategory of developmental disorders. It is similar to classic autism in that people with Asperger's disorder have difficulties with social interaction and display restricted, stereotyped patterns of behaviour and interests. Asperger's disorder is different from autism because people with Asperger's disorder have normal language and intellectual skills. The *DSM-5*, released in May 2013, replaces autistic disorder, Asperger's disorder, childhood disintegrative disorder and pervasive developmental disorder (not otherwise specified) with a single category: autism spectrum disorder. Autism spectrum disorder will be classified in terms of symptom severity (American Psychiatric Association [APA], 2012).

Approximately one in 88 children has an autism spectrum disorder (Centers for Disease Control and Prevention, 2012), with one in three also having an intellectual disability.

People with autism spectrum disorder often have difficulties learning skills required to live independently. Treatments such as behavioural intervention have been developed to help teach these skills. There is a lot of debate about whether autism spectrum disorder can be cured or whether it is a disability that requires specific supports for life. There is no easy answer to this question. What is most important is that people with an autism spectrum disorder be given the opportunities and help to live as independently and successfully as possible in their community.

Developmental disability

Fetal alcohol spectrum disorder

Fetal alcohol spectrum disorder (FASD) is a term that describes the range of effects that can occur in a person who was exposed to alcohol as a fetus. Effects may include physical, emotional, behavioural and/or cognitive disabilities. FASD is an umbrella term that refers to several conditions, the most common of which is fetal alcohol syndrome (FAS). People with FAS have specific facial features, growth features and impaired cognitive functioning. This can include problems with memory, learning and attention. Some people with FASD have an intellectual disability, while others do not.

For more information about FASD and mental health, read *Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis*. This primer, published by the Center for Substance Abuse Prevention, is available at www.fasdcenter.samhsa.gov/documents/WYNKDiagnosis_5_colorJA_new.pdf.

WHY DO PEOPLE HAVE DEVELOPMENTAL DISABILITIES?

It is often helpful to see a person's difficulties as coming from biological, psychological and social sources. As this biopsychosocial model suggests, the causes of developmental disabilities are complex.

The biopsychosocial approach to understanding developmental disability

BIOLOGICAL FACTORS

Some genetic abnormalities are passed down from parents (like the one found in people with Fragile X syndrome). Sometimes we know exactly what gene is passed from parent to child. Other times we only know that the problem runs in families, but do not yet know exactly what is being passed along. Other genetic problems occur when the egg is fertilized, but do not come from the mother or father (as with Down syndrome). For some people, the genetic cause hasn't been identified yet. Some people may have had a traumatic brain injury in childhood. Others may be exposed to alcohol and other drugs or other dangers prenatally, which can affect intellectual functioning.

PSYCHOLOGICAL FACTORS

People with developmental disabilities often think in ways that are different than what would be expected from their peers who do not have developmental disabilities. Often this means that a person with a developmental disability will have significantly more

trouble problem solving and reasoning about concepts than their peers. A lack of learning and environmental stimulation in childhood (such as in cases of extreme neglect) can also affect intellectual functioning.

SOCIAL FACTORS

Culture plays a part in defining “disability.” Many societal barriers exist that make it difficult for a person with biological and psychological limitations to be independent. For example, when someone who needs a wheelchair is confronted with physical obstacles, such as stairs and doors that are too small, their disability is more pronounced and causes them greater trouble. However, if the same location were built with ramps, an elevator and large enough entrance ways, that same person would have much more success being included in the community and being independent. In the same way, a person with a developmental disability who is confronted with obstacles will have more trouble, and their disability will be more evident. For example, the person might find reading long words difficult, and as a result, may not understand instructions. If the instructions were shown using pictures and straightforward language, that person might be able to do the task independently. The social contributions to disability can be addressed by providing appropriate supports in the community and maximizing the fit between a person’s skills and the demands placed upon them.

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Mental health problems

3

Outline

- Why do people develop mental health problems?
- Determining whether there is a mental health disorder

WHY DO PEOPLE DEVELOP MENTAL HEALTH PROBLEMS?

We don't know exactly what causes mental health problems, nor can we predict who will have a few episodes and who will develop chronic problems. However, it is becoming more apparent that a mix of biological, psychological and social factors influences the development of mental health problems. That is why the biopsychosocial approach can be helpful in understanding key factors in what can be a very complex explanation. One way of explaining how these factors influence one another is to look at stress and vulnerability.

The stress-vulnerability model

In general, the stress-vulnerability model holds that the greater the number of possible causes that are present, the greater the risk that a person will develop a mental health problem.

Treatment for mental health problems involves finding ways to decrease vulnerability (e.g., learning coping skills or using medication to help balance chemical processes in the brain) and decrease stress factors (e.g., developing a strong social network, avoiding dangerous situations).

VULNERABILITY

Biological factors

Biological vulnerability is the tendency to develop problems in a specific area of the body—for example, respiratory system problems such as asthma. Similarly, people can have a biological tendency to develop mental health problems such as depression, bipolar disorder or schizophrenia.

Vulnerability doesn't mean that problems will happen. It means that if certain factors come together, a person has a higher risk of developing a problem, and a higher risk of the problem being more severe.

Genetics

Some mental health problems seem to be genetic, or run in families. For example, the rate of schizophrenia in the general population is about one per cent. That rises to nine per cent for a child with one sibling with the diagnosis, 13 per cent for a child with one parent with the diagnosis and 46 per cent for a child with both parents with the diagnosis.

Mental health problems

Some genetic disorders that cause developmental disability can predispose a person to having specific mental health problems. For example, someone who has Fragile X syndrome is at increased risk for developing social anxiety, and someone with 22q11 deletion is at increased risk for developing schizophrenia. This is one reason why it is very important to know the cause of a person's developmental disability. We did not have the technology 20 years ago to recognize many of the syndromes that we can now identify, so there may be some people with dual diagnosis who have a genetic disorder that has not been diagnosed.

At least nine genetic conditions have been shown to overlap with mental health problems and challenging behaviours (Dykens et al., 2000).

Table 3-1: Genetic syndromes and dual diagnosis

Syndrome	Aggression	Self-injury	Anxiety disorder, phobias	Alzheimer's disease	Depression, mania, bipolar disorder	Schizophrenia
5p	X	X				
Prader-Willi	X	X	X		X	
William	X		X		X	
Smith-Magenis	X	X				
Lesch-Neyhan		X				
Turner			X			
Fragile X		X	X		X	
22q11 deletion (velocardiofacial)				X	X	X
Down			X	X	X	
Cornelia de Lange		X				
Rett		X				

Mental health problems

Brain chemistry

Research indicates that chemical processes in the brain are involved in the development of mental health problems. Recent research has also pointed to abnormalities in brain structure as a possible factor in the development of mental health problems, particularly schizophrenia. Because people with developmental disabilities have physical brain structures and chemical processes that are different than a neurotypically developing person, they might also be predisposed to having mental health problems.

Medical vulnerabilities

People with developmental disabilities have a higher incidence of medical conditions compared to the general population (Kerr, 2006). Unfortunately, medical problems are often missed in people with developmental disabilities because of communication impairments and may be misattributed as “behaviour problems.” Unidentified medical conditions may be one reason for referral for psychiatric assessment and treatment.

Medical vulnerabilities: Seizures

Seizures are more common among people who have developmental disabilities than in the general population. Prevalence rates range from 14 per cent to 40 per cent (Deb et al., 2001; Espie et al., 2003). There is a complex relationship between epilepsy and mental health problems among people with developmental disabilities, which may reflect the underlying brain disorder causing the seizures rather than the epilepsy itself (Deb & Hunter, 1991a, b, c). Seizure disorders are important to consider, as they may be one explanation for a person’s problematic behaviour.

Psychological factors

The temperament a person is born with (e.g., a tendency to internalize feelings) may play a part in increasing the risk of developing mental health problems. Some psychological risk factors interact with life stressors and biological predispositions by reducing a person’s ability to cope with stressors and be resilient. Psychological risk factors include:

- poor social skills
- poor coping skills and self-soothing skills
- poor problem-solving skills
- problems with communication
- low self-esteem.

Stress

Although stress does not cause mental health problems, it can trigger them or make them worse. People with developmental disabilities experience a lot of stress in their lives and may have an even more difficult time coping with stress than do people in the general population.

Social factors

Events in childhood or adulthood can contribute to the onset of a mental health problem. Negative life events have been tied to the development of mental health problems in people with developmental disabilities (see Hulbert-Williams & Hastings, 2008). Research suggests that early childhood trauma and losses, such as the death or separation of parents, or adult events, such as the death of a family member or loss of a job or day activity, can be precursors to a mental health problem. Minor daily hassles may also be highly relevant for people with developmental disabilities. Conflicts with family members, residents or staff members may be an important area of concern for people with dual diagnosis.

Other environmental risk factors include living in poverty and lacking social support. Poverty is clearly a factor related to the mental health of people with developmental disabilities. They are more likely to live in poverty and experience poorer housing conditions and higher exposure to high-crime areas compared to the general population (Robinson & Rathbone, 1999).

Physical, sexual and psychological abuse

People with developmental disabilities are at increased risk for maltreatment and neglect. Those admitted to psychiatric hospitals, as well as those living in the community, should be screened for a history of maltreatment.

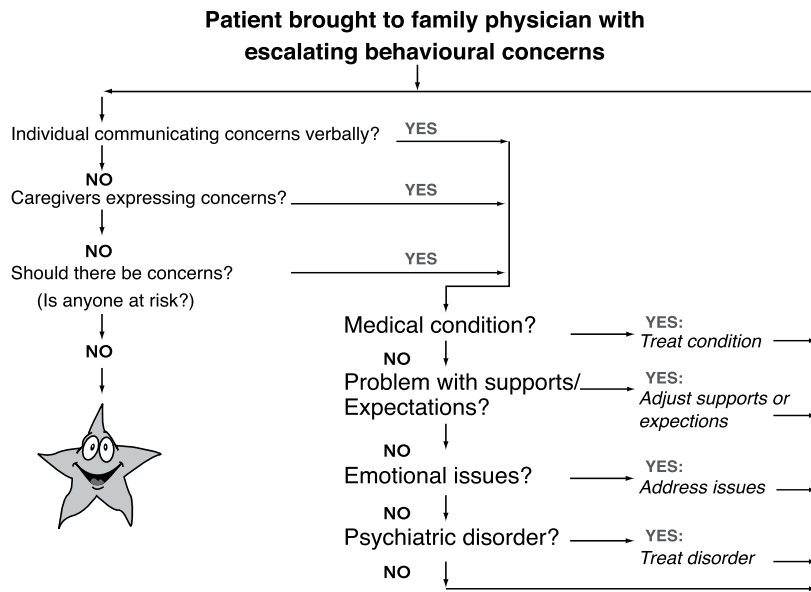
Transition from adolescence to adulthood

In the general population, the transition from adolescence to young adulthood (16 to 25) is a high-risk period for mental health problems. This risk is higher in young adults with developmental disabilities (Masi, 1998), and young adulthood is the most likely time for psychiatric hospitalization in this population (Lunsky & Balogh, 2010). People with developmental disabilities are affected by the stresses of puberty, as well as by the specific stresses associated with transitioning from the child to adult service system, which often means losing school supports and not getting sufficient services (Fletcher, 1993). This transition may also be a period of increased stress on the family and parents (McIntyre et al., 2002).

DETERMINING WHETHER THERE IS A MENTAL HEALTH DISORDER

There are steps that clinicians can take to better understand how biological, psychological and social factors can impact a person’s mental health. These steps are often described to health professionals as a “decision tree,” and include the following four questions (Bradley & Burke, 2002).

Figure 3-1: Diagnostic formulation of behavioural concerns



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1. Is there a medical problem?

Many people with developmental disabilities have physical health concerns that can go unnoticed or undertreated. Before deciding that a person’s problematic behaviour is a result of a mental health problem, it is important to treat any physical health issues. For example, if a person is constipated but unable to communicate their discomfort to others, they might become aggressive and lash out at others. Before considering whether the person has mental health problems, it would be important to relieve them of the constipation and resulting discomfort. Ask doctors to first perform a full physical exam if you are concerned about mental health problems.

2. Is there a problem with supports and appropriate expectations?

After checking for and treating physical conditions, it is important to examine how the supports a person is receiving (or not receiving) influences their behaviour. If a person

is unable to do the things that are meaningful for them or expected of them because services or supports are not available, then they may become anxious, angry or sad. For example, if a person with a developmental disability has a job packaging materials and needs help with structure and reminders to do well, they might become very upset if they cannot get that help. Does this person have needs that are not being met? How can services be optimized for them?

3. Is there an emotional problem?

There is a difference between having an emotional problem and a psychiatric disorder. We all experience times in our lives when we feel intense negative emotions, such as anger, sadness or anxiety. Sometimes, we can experience these feelings because of stressful things that are going on around us (e.g., moving, loss of a loved one, neglect or abuse). Other times, we feel these ways because of what is going on inside of us (e.g., feeling inadequate, low self-esteem). When we have intense negative feelings, we are experiencing an emotional problem, and we look for ways to address it. For example, we can use our social supports or a specific coping strategy and the negative feeling goes away. When we try a number of things and nothing seems to help, then an emotional problem can turn into a mental health problem or psychiatric disorder.

4. Is there a psychiatric disorder?

There is no clear line that indicates when a problem becomes severe enough to be described as a psychiatric disorder. If emotional problems are not recognized and addressed, they can increase in intensity and severely impact the person and those around them.

Categorical approaches

Many clinicians use the *DSM* diagnostic criteria to help screen and assess people for psychiatric disorders. Most people with mental health problems will receive a specific diagnosis at some point during treatment. However, because the symptoms of many disorders are similar, the diagnosis may change several times during the course of treatment. Clinicians who work with people with developmental disabilities may also use the *Diagnostic Manual—Intellectual Disability* ([*DM-ID*]; Fletcher et al., 2007), which suggests adaptations to the *DSM-IV* for people with intellectual disabilities. Clinicians may also use the *Diagnostic Criteria for Learning Disability (DC-LD)*, which was developed in the United Kingdom (Royal College of Psychiatrists (2001).

Mental health problems

Dimensional approaches

Another way to understand mental health problems is to divide them into broad groups based on the behaviours that we see. Skinner (2005) suggests dividing mental health problems into four groups:

- anxiety
- mood
- psychosis
- impulsivity.

Mental health problems are described in terms of the severity of behaviours in each of these groups. This dimensional approach is a useful way to begin to organize the observations that indicate that a person has a mental health problem.

Table 3-2: The dimensional approach

DIMENSION	VERBAL BEHAVIOUR	MENTAL HEALTH PROBLEMS
		Axis I: Mental Health Disorders
Anxiety	• “fear talk”	• anxiety disorders (e.g., phobias, obsessive-compulsive disorder)
Mood	• “sad talk” • laconia • “manic or grandiose talk”	• depressive disorders • dysthymia • bipolar disorders
Psychosis	• “weird talk”	• schizophrenia • other psychotic disorders • mania
Impulsivity	• “threat talk”	• impulse control disorders • gambling • bulimia • alcohol or other drug abuse/dependence

Anxiety

Anxiety disorders take on different forms. They are the most common type of mental health disorder. They have different causes and symptoms, but one thing they have in common is that they cause feelings of deep anxiety and fear that affect a person's mood, thinking and behaviour. When someone has an anxiety disorder, their thoughts and feelings may get in the way of taking the actions needed to be healthy and productive. These illnesses are chronic and can get worse over time if they are not treated.

Sometimes it is difficult to recognize anxiety disorders in people with developmental disabilities because some of the diagnostic criteria that is used to make the diagnosis depends on being able to express very complex ideas, like describing depersonalization (Fletcher et al., 2007). However, all types of anxiety disorders have been noted in people with developmental disabilities, including these:

- posttraumatic stress disorder
- generalized anxiety disorder
- panic disorder
- social phobia
- obsessive-compulsive disorder.

POSTTRAUMATIC STRESS DISORDER

People with developmental disabilities may experience sexual, physical, psychological or emotional trauma. Experiencing a traumatic event may trigger mental health problems such as anxiety, depression, psychotic symptoms or personality disorders (Substance Abuse and Mental Health Services Administration, 2003). Posttraumatic stress disorder (PTSD) describes a set of symptoms that people may experience following a traumatic event.

Crises that threaten the safety of the person with PTSD (e.g., talking about suicide) or the safety of others (e.g., reacting violently when they feel threatened) must be addressed first. However, treatment works best when both PTSD and other problems are addressed at the same time.

GENERALIZED ANXIETY DISORDER

People who have experienced at least six months of ongoing and excessive anxiety and tension may have generalized anxiety disorder. They usually expect the worst and worry about things, even when there is no sign of problems. They often suffer from the following symptoms:

- insomnia
- fatigue
- trembling
- muscle tension
- headaches
- irritability
- hot flashes.

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PANIC DISORDER

Panic disorder occurs when people have repeated panic attacks, which feature the sudden onset of intense fear or terror. During these attacks, people may experience physical symptoms, such as:

- shortness of breath
- heart palpitations
- chest pain or discomfort
- choking or smothering sensations
- fear of losing control
- fear of going crazy.

Many people with panic disorder develop anxieties about places or situations in which they fear another attack, or where they might not be able to get help. Eventually this can develop into agoraphobia, a fear of going into open or public spaces. Women are twice as likely as men to develop panic disorder, which usually begins in young adulthood.

SOCIAL PHOBIA

People with social phobia experience a significant amount of anxiety and self-consciousness in everyday social situations. They worry about being judged by others and embarrassed by their own actions. This anxiety can lead them to avoid potentially humiliating situations. People with social phobia may experience other symptoms, including:

- blushing
- sweating
- trembling
- problems talking
- nausea.

Major depressive disorder

Symptoms

The Diagnostic Manual Intellectual Ability (DM-ID) suggests that four or more symptoms need to be present during the same two-week period and represent a change from previous functioning.

- At least one of the symptoms needs to be depressed mood, which can be different than sadness; loss of interest or pleasure; or irritable mood.
 - Depressed mood can be described in a number of ways: sad facial expressions, flat affect or absence of emotional expression, rarely smiling or laughing or crying and appearing tearful. Remember that these behaviours need to be observed as changes from what the person typically shows (different from their baseline functioning).
 - Changes in irritability can include: appearing grouchy and having an angry facial expression, an increase in agitated behaviours (e.g., self-injury, spitting, yelling, swearing, destructive behaviours) that are accompanied by angry emotions.
- Weight loss or gain: Many people lose weight when they are depressed, partly because they lose their appetite. However, some people feel hungrier and may crave carbohydrate-rich foods, which cause them to gain weight. Depending on the type of depression, a person's metabolism may speed up or slow down, which can cause weight loss or gain. During the two-week period, has the person changed their eating habits? Is the person eating to excess, stealing food or refusing meals?
- Sleep problems: Sleep problems are common in depression. Many people have insomnia. They have trouble falling asleep, wake up often during the night or wake up very early. They do not find sleep to be restful and may wake up feeling exhausted. Other people sleep too much, especially during the day. This is called hypersomnia.
- Physical changes: For some people with depression, their movements, speech and/or thinking slow down. In severe cases, people may be unable to move, speak or respond. With other people, the opposite happens. They become agitated and cannot sit still. They may pace, wring their hands or show their agitation in other ways.
- Loss of energy: People with depression find it difficult to complete everyday activities because they lack energy or drive. They may appear tired or confused. They may become agitated about activities that require physical effort or spend excessive time just sitting or lying down.
- Feelings of worthlessness and guilt: People who are depressed may lack self-confidence. They may not assert themselves and may be overwhelmed by feelings of worthlessness. Many cannot stop thinking about past events. They obsess about having let others down or having said the wrong things, and they

Mental health problems

feel guilty. A person with a developmental disability who is depressed may make negative self-statements, have unrealistic fears that caretakers will be angry or rejecting and excessively seek reassurance.

- Diminished ability to think or concentrate: People with depression may have reduced productivity at work or in a day program. They may also have diminished self-care skills. They may be unable to complete usual tasks or may experience an unexplained skill loss or an uncharacteristic inability to learn new skills.
- Suicidal thoughts: People with depression often think that life is not worth living or that they would be better off dead. There is a high risk that they will act on these thoughts. Many people do try to kill themselves when they are depressed.

Other symptoms of depression may include:

- oversensitivity and preoccupation with oneself
- negative thinking
- little response to reassurance, support, feedback or sympathy
- less awareness of others' feelings because of their own internal pain
- feeling a need to control relationships
- inability to function in a normal role.

Bipolar disorder

Symptoms

There are three major groups of symptoms related to bipolar disorder: mania, hypomania and depression.

Mania

If a person's mood is abnormally or persistently high for at least one week, they may be in a manic phase of the illness. However, not everyone who enters the manic phase feels euphoric. Some people may feel extremely irritable, behave rudely or become angry, disruptive and aggressive. They can be very impatient with others and make hurtful statements or behave impulsively or even dangerously.

In addition to experiencing mood symptoms, people must have at least three of the following symptoms to a significant degree in order to be diagnosed with bipolar disorder:

- exaggerated self-esteem or grandiosity
- reduced need for sleep
- increased talkativeness
- a flood of ideas or racing thoughts

- speeding up of activities such as talking and thinking, which may be disorganized
- poor judgment
- psychotic symptoms such as delusions (false beliefs) and in some cases hallucinations (mainly hearing voices).

Mania causes people to be emotional and react strongly to situations. For people with poor anger management skills or with low tolerance for frustration, this can lead to violent behaviour.

Hypomania

Hypomania is a milder form of mania with less severe symptoms. However, symptoms can interfere with the person's ability to function. Hypomania has recently been acknowledged as having more impact on a person's life and relationships than was previously recognized.

The manic/hypomanic, depressive and mixed (both manic/hypomanic and depressive) states usually do not occur in a particular order. How often they occur cannot be predicted. For many people, there are years between each episode, whereas others have episodes more often. Over a lifetime, the average person with bipolar disorder experiences about 10 episodes of depression and mania/hypomania or mixed states. As the person ages, the episodes come closer together. Untreated manias often last for two or three months. Untreated depressions usually last between four and six months.

Psychosis

A psychotic disorder is a severe medical illness that disturbs the way a person acts, thinks, sees, hears or feels, and makes it difficult or impossible for him or her to distinguish between what is real and what is not.

Symptoms of psychosis may be either positive (something "added to" the person, something that is not always present) or negative (something "taken away or missing from" the person). A diagnosis of psychotic disorder may be incorrectly made because of the challenges in making the diagnosis in people with developmental disabilities, particularly by clinicians with less training in developmental disability. Careful observation and questioning are required to correctly diagnose psychotic disorder in someone with a developmental disability. It is particularly difficult to make a diagnosis of psychosis in a person who is lower functioning and does not have the ability to articulate their inner experience (where hallucinations or delusions occur).

Mental health problems

Schizophrenia

Symptoms

Early warning signs of schizophrenia include:

- withdrawal from regular activities and from family and friends
- problems concentrating
- lack of energy
- confusion
- sleep problems
- unusual speech, thoughts or behaviour (e.g., may become intensely preoccupied with religion or philosophy).

This early phase can last weeks or months.

The seriousness of symptoms and the chronic nature of schizophrenia can often cause a high degree of disability. Coping can also be difficult for family members who remember the person before the illness.

Positive symptoms (symptoms that appear in a person) include:

Delusions: A delusion is a false or irrational personal belief. About one third of people with schizophrenia experience delusions. These can include feelings of being persecuted, cheated or harassed, as well as delusions of grandeur (a false idea of oneself, e.g., as being famous).

Hallucinations: A hallucination occurs when a person hears, sees, tastes or experiences something that is not really there. Hearing voices is the most common hallucination.

Disordered thoughts: A person's thoughts may become unconnected, so that conversations no longer make sense. Their thoughts may come and go and they may not be able to focus for long on one thought. This is called *thought disorder*. It can contribute to a person's isolation.

Cognitive difficulties: A person may have problems with memory, concentration and understanding concepts.

Decline in social or occupational functioning: A person may have problems with work or school, or have trouble with self-care.

Disorganized behaviour: A person may seem agitated for no particular reason.

Negative symptoms (elements that are taken away from a person) often include “blunted” or “flat” affect. This means that the person finds it hard to show or express feelings. They may feel empty. They may also appear extremely apathetic, have reduced motivation and withdraw socially.

Men and women are equally likely to develop schizophrenia. However, men tend to have their first episode in their late teens or early 20s. The onset for women is usually a few years later. In most cases, the illness and its symptoms can appear so gradually that the person and their family may not be aware of the illness for a long time.

Symptoms of schizophrenia tend to vary in intensity over time. Some people have a mild form of schizophrenia and may only have symptoms for a few short periods during their lives. Others experience symptoms almost all of the time and may need to spend time in a hospital to protect themselves or others.

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How dual diagnosis affects family life

4

Outline

- Family relationships
- Impact on caregivers

How dual diagnosis affects family life

When families learn that a family member has both a psychiatric disorder and a developmental disability, they often feel shocked and scared. Psychiatric disorders on their own can overwhelm families. Families that have worked very hard to develop a safe and comfortable daily routine that works for them and their family member with a developmental disability may find themselves on an emotional roller coaster.

A growing body of knowledge highlights what many families already know too well: that mental health problems or challenging behaviours contribute to family conflict, wear away social support and can have a negative effect on the mental health and well-being of family members.

FAMILY RELATIONSHIPS

Parents

Parents of people with developmental disabilities work very hard to co-ordinate services and care for their child. When this child also develops mental health problems or serious challenging behaviours, parents can struggle to cope. They often describe feeling frustrated, angry, hopeless, stressed, sad or overwhelmed.

They can also report feeling empowered and secure. Each parent (and family) reaction depends on the problems at hand, as well as on coping skills, strategies and resources and other life events that surround that family. Parents feel a tremendous sense of responsibility and worry about their child's care and well-being across the lifespan. Over time, the chronic nature of the problems can take its toll.

My daughter needs support too. The rest of the family needs support. My husband has depression and I'm sure that it would be different if his life wasn't so stressful. And I feel like I'm an Atlas holding up the world. . . . I am holding the family together, and I need a break, but I can't. I need to be strong enough . . . until what? Never ends.

When a child with a developmental disability develops mental health problems, the added strain can affect the parents' relationship as well as the functioning of the whole family. On the other hand, caring for a child with high-level needs may bring some spouses closer together.

Helping families cope

In the book *More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs*, Baskin and Fawcett (2006) suggest a number of strategies to help families remain healthy and cohesive:

- Keep the lines of communication open between partners.
- Rely on each other for support.
- Seek help from each other or from others outside the relationship.
- Make time for each other, like going to a movie or another activity to nurture your relationship.
- Attend some of your child's appointments together.
- Give each other time to deal with stress in your own way.
- Try hands-on activities instead of only talk.
- Learn about your child's difficulties together.
- Ask for information to share with each other.
- Increase your partner's involvement slowly, rather than expecting too much too soon.
- Connect with other families of people in the same situation as you.
- See yourself as a "parenting team."
- Celebrate your differences.
- Remember the big picture of what your common goals are for your child.
- Recognize that sometimes family members have uneven parenting responsibilities, and parents should communicate with each other about what their expectations they hold.

Baskin and Fawcett (2006) also make a number of suggestions about how a couple might find time and energy to nurture their relationship. It is important to foster your connection to your partner, including developing different ways of making time to connect to each other.

Siblings

Siblings may worry about developing mental health problems. They may worry about the stress and strain that their parents are enduring and may take on the burden of trying to help. At the same time, brothers and sisters sometimes resent the time that parents spend supporting their sibling with a dual diagnosis. They may become angry to the point of acting out or distancing themselves from family and friends.

It has affected his sister who was most concerned and impacted, but now she is ok because we got her an apartment. My other son had to move out of the home for a year because of the stress.

How dual diagnosis affects family life

Siblings may also experience anger, hostility or verbal or physical aggression from their brother or sister with dual diagnosis. These behaviours can evoke shock, dismay, fear and a sense of abandonment and rejection. Sometimes, children may feel like they have lost their best friend. They may also feel guilty that they have a better life than their brother or sister.

Helping children cope

Parents can help their other children by:

- assuring them that behaviours such as aggression are symptoms of the illness and shouldn't be taken personally
- sharing feelings and encouraging their children to talk about how they feel and about how their brother's or sister's problems are affecting them
- explaining that family members often feel uncomfortable, embarrassed or ashamed of their ill sibling's behaviours, symptoms and diagnosis
- discussing the issue of stigma and why it happens, as well as effective ways to deal with it
- helping them learn about developmental disability and mental health problems and how these interact with and affect each other
- spending time alone with their children, talking and doing enjoyable activities
- helping them build a new relationship with their brother or sister and creating unique ways of being with their sibling.

Don Meyer has developed the [Sibling Support Project](#), which provides sibling workshops and offers resources on how to support siblings of people with developmental disabilities. He has also developed some excellent books for child siblings (*Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*) and adult siblings (*Thicker Than Water: Essays by Adult Siblings of People with Disabilities*). The project also includes child and adult sibling listservs.

Baskin and Fawcett (2006) devote a chapter of their book to supporting siblings of people with special needs. They suggest the following ways of supporting all children and maintaining a strong family life:

- Have realistic expectations of your typical developing children. Some siblings may feel like they have to behave perfectly or excel at school in order to “make up for” their brother or sister with special needs.
- Celebrate the accomplishments and achievements of all children in the family.
- Encourage siblings to have interests outside of the family. An outside activity can help build friendships, skills and self-esteem.
- Strengthen your child's support system. Sometimes it's important for siblings to have an adult outside of the family (e.g., a guidance counsellor or social worker at school) for siblings to confide in.
- Help your child establish a peer group. Introducing your child to others who also have

How dual diagnosis affects family life

a brother or sister with a similar disability can help them to understand their own experiences.

Baskin & Fawcett (2006) also discuss siblings' caregiving responsibilities. They suggest giving siblings a say in the amount of family responsibility they have to accept. For example, a weekly family meeting might allow for everyone to discuss each person's plans, needs and responsibilities. They also offer creative strategies for regaining family balance and making sure that siblings also receive "quality time," including arranging dates with each child alone and mixing errands with one-on-one time.

IMPACT ON CAREGIVERS

Some family members may find it almost impossible to soothe their own anxieties and to distract themselves from the strain of coping with their ill family member. They may feel unable or too guilty to take time for themselves, to relax, care for their own emotional and physical health and rebuild their own coping resources. Sometimes, family members feel guilt when they experience negative emotions, such as resentment or anger, toward their child. It is very important for parents to admit to themselves when they feel extremely tired, worn out, angry or bitter. Denying these negative emotions may seem to help in the short term but can lead to exhaustion, depression, isolation and hopelessness.

Parents can find themselves feeling isolated from others who were once very good friends. They may feel that they don't have the time to maintain friendships, or they may be embarrassed or ashamed about their child's dual diagnosis.

Think about your own situation and how your life has been affected. Remember that all family members experience difficult circumstances and negative feelings. It is very common for family members to feel guilty when they are asked to think about how the situation has affected their own lives. However, before you can begin to take care of yourself and play a positive role in your ill family member's recovery, you need to think honestly about how your life has changed.

How dual diagnosis affects family life

Caregiver burden and compassion fatigue: A note about language

The term *caregiver burden* is used in professional literature to describe the emotional, social and psychological toll on a family that comes from caring for someone with a mental health problem. Many caregivers want others to recognize how difficult it is to care for an ill family member with dual diagnosis, but don't like the term "caregiver burden." They feel it ignores the positive side of looking after the needs of someone important to them and negates the fact that, in spite of the stress, they love the person and would go to the ends of the earth to help and protect them. It also dehumanizes their loved one, and reduces them to a "burden," which the caregiver hopes will not always be the case.

The stress and feelings of powerlessness that are such a large part of caring for a family member with dual diagnosis may be better described as *compassion fatigue*. We use that term to describe the overwhelming physical, emotional, social and spiritual exhaustion that can strike family members affected by dual diagnosis. It is a much more user-friendly term for describing the results of coping on an ongoing basis with extreme adversity.

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Activity 4-1: Personal impact log

This log will help you to think about the effects of your family member’s mental health problems on your own physical, emotional, social and spiritual health. It will help you to break the overall impact on your life into smaller areas of concern that will be more manageable.

Below is an example of a personal impact log.

PERSONAL IMPACT LOG	
Physical health	Emotional health
<ul style="list-style-type: none"> • chest pain has returned—too worried about my son • no time to go to my own doctor anymore • no longer exercising • always tired • can’t sleep without taking sleeping medication (never used to need anything to sleep) • joint stiffness and neck pain • eating high-sugar foods; don’t care about my diet anymore 	<ul style="list-style-type: none"> • constant worrying about Kevin • worry about everything now • bad anxiety and sadness • always angry or frustrated or depressed these days • snapping at other children and then feel guilty • angry with my partner—he/she gets to leave for work all day and I have to deal with all of our problems
Social life	Spiritual life
<ul style="list-style-type: none"> • never go out with spouse or close friends anymore • never have guests over for dinner or Friday “euchre nights” • can’t concentrate on reading • spend all of our time in emergency rooms or visiting Kevin on psychiatric wards 	<ul style="list-style-type: none"> • do not know what this is anymore! • don’t go to church • no time for my daily meditation readings • don’t feel like doing my yoga sessions anymore • bitter and resentful about my son’s illness—why our family? • angry with God

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On the blank personal impact log, write down the ways your life has been affected in the areas that apply to you. You may find that you fill in only some of the areas.

You will use this information again as you work through the self-care plan in the next chapter.

PERSONAL IMPACT LOG	
Physical health	Emotional health
Social life	Spiritual life

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Paying attention to where you and your family are in terms of the impact of compassion fatigue can be helpful for a number of reasons. It can help you to communicate with professionals about your support needs. It can also help to monitor how you are doing when you put things in place to reduce the negative impact of caregiving and enhance the positive impact.

You can use the Brief Family Distress Scale (Weiss & Lunsky, 2011) to quickly decide where you are in terms of crisis, which is often the result of ongoing stressors and a failure to cope successfully. This scale is like a “distress thermometer” and offers a quick way to communicate to others, including service providers, how well you think you are managing and how urgently you feel that you need assistance.

Brief Family Distress Scale

On a scale of 1 to 10, rate where you and your family are right now in terms of crisis by picking one of the following statements:

1. Everything is fine, my family and I are not in crisis at all.
2. Everything is fine, but sometimes we have our difficulties.
3. Things are sometimes stressful, but we can deal with problems if they arise.
4. Things are often stressful, but we are managing to deal with problems when they arise.
5. Things are very stressful, but we are getting by with a lot of effort.
6. We have to work extremely hard every moment of every day to avoid having a crisis.
7. We won't be able to handle things soon. If one more thing goes wrong—we will be in crisis.
8. We are currently in crisis, but are dealing with it ourselves.
9. We are currently in crisis, and have asked for help from crisis services (emergency room, hospital, community crisis supports).
10. We are currently in crisis, and it could not get any worse.

How dual diagnosis affects family life

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Self-care

5

OUTLINE

- Resilience
- Short-term self-care strategies
- Long-term self-care goals
- Building a self-care plan

Self-care

We have already discussed the enormous challenges involved in having a family member with dual diagnosis. You and your family should never underestimate the benefits of taking care of yourselves. Taking good care of yourself gives you more physical and emotional energy to deal with the challenges you face, and that will benefit your ill family member. Family members will each find their own way to care for themselves. Being able to soothe, relax and calm yourself involves:

- knowing what kinds of thoughts and behaviours make you feel better or worse
- coming up with a self-care plan that helps you to prevent or overcome the negative feelings.

This plan involves following a structured routine each day, engaging in a particular activity, spending time with a good friend or focusing on a way of thinking—anything that may comfort you and give you a sense of well-being and stability. We will develop a self-care plan later in this chapter.

RESILIENCE

The strongest oak of the forest is not the one that is protected from the storm and hidden from the sun. It is the one that stands in the open, where it is compelled to struggle for its existence against the winds and rains and the scorching sun.

—Napoleon Hill (1883–1970)

What is resilience?

Resilience is frequently described as the capacity to thrive and fulfill one's potential, despite (or perhaps because of), stressful circumstances. All of us are resilient in one way or another, but some people seem to be more so. They are inclined to see challenges as learning opportunities that can lead to healthy emotional growth and development.

In their book *Building a Joyful Life with Your Child Who Has Special Needs*, Whiteman and Roan-Yager (2007) explain resilience as distinct clusters of strength and qualities found in resilient parents when faced with stressful situations:

Insight: The ability to ask tough questions and give honest answers. It includes understanding, empathy and a tolerance for ambiguity.

Independence: The ability to separate oneself emotionally and physically from the source of pain. This includes the ability to acknowledge the stressor, step back from it and develop alternative ways of viewing the situation.

Relationships: The ability to develop meaningful relationships is an important component of mental health. This includes the ability to find people who support, sustain and validate us.

Initiative: The ability to take charge of problems in a proactive way. This talent for tackling challenging situations often includes problem solving skills and sheer persistence.

Creativity and humour: Creativity involves using imagination to express our feelings. Many use some type of art form—painting, dancing or collage—to express their feelings through creativity. Humour, described as finding the comic in the tragic, is an essential part of getting through daily challenges.

Morality: Acting on the basis of an informed conscience, a sense of obligation to contribute to the well-being of others. Many resilient people have transformed their situations into conscious action in the world.

Factors that are characteristic of resilient people include:

- a sense of closeness and connectedness to others
- strong, dependable support from at least one significant other in their lives
- attention to their own personal health and well-being
- high self-esteem
- a strong sense of personal identity
- a realistic and balanced awareness of their strengths and limitations
- the ability to be assertive and emotionally tough when necessary, but also sensitive and compassionate
- a playful, lighthearted approach to life
- a sense of direction and purpose in life
- the ability to turn difficult experiences into valuable learning opportunities
- the capacity to pick themselves up, shake themselves off and keep moving forward after traumatic and upsetting situations
- the ability to adapt to live comfortably with uncertainty and unpredictability
- the ability to laugh at themselves. Resilient people do not “sweat the small stuff.”

A sense of humor can help you overlook the unattractive, tolerate the unpleasant, cope with the unexpected and smile through the unbearable.

—Moshe Waldoks

Developing resilience

Ask yourself:

- How resilient am I?
- In what specific ways am I very resilient?
- In what ways am I less resilient and how can I change this?

Activity 5-1: Assessing resilience

Developed by Patricia Morgan

To help you answer these questions, try filling out a resiliency questionnaire or quiz. There are many tools designed to help you assess your personal level of resilience. We have included just one of these quizzes in this chapter.

Resilience is the ability to recover or bounce back from and effectively adapt to life changes and challenges. Anyone can strengthen their resiliency. Celebrate the resilient aspects you have in place and take action to improve the rest.

Rate yourself in the following areas:

Never (0) Seldom (1) Sometimes (2) Frequently (3) Always (4)

Attend to Your Body

1. I recognize when my body is feeling distress _____
2. I deliberately relax my body when I realize it is strained _____
3. I eat a wholesome diet _____
4. I get adequate rest _____
5. I routinely exercise _____

Attend to Your Inner Self

6. I take charge of my thoughts in stressful situations _____
7. I recognize when I talk to myself in a criticizing or shaming manner _____
8. I minimize my critical self talk and increase my supportive self talk _____

9. I know what my main strengths or gifts are
(example: assertive, disciplined, honest, organized) _____

10. I use and volunteer my strengths or gifts _____

Attend to Your Communication

11. I change negative comments into positive phrasing _____

12. I listen to others and communicate clearly my position _____

13. I work towards finding a mutual agreement in conflicts _____

14. I minimize my criticism of others while offering
helpful feedback _____

15. I assert myself by saying “yes,” “no” or “I will think
it over” _____

Attend to Your Social Support

16. I feel close and connected to significant others _____

17. I give and receive help, support and listening time at
home and at work _____

18. I express appreciation to others at home and work _____

19. I encourage and act as a team cheer leader at home
and work _____

20. I say “I am sorry” and make amends when I make mistakes _____

Attend to Giving Your Life Meaning

21. I learn and give meaning to mistakes, hurts and
disappointments _____

22. I view work, relationships and life with realistic optimism _____

23. I set and meet realistic goals and expectations _____

24. I laugh at myself while taking my responsibilities seriously _____

25. I find health, optimism, pleasure, gratitude and meaning
in my life _____

INTERPRETING YOUR SCORE

Bounce Back Champ (Score from 75 to 100). Congratulations! You have developed a strong resilience factor. You know that it takes daily effort to bounce back from big and little strains. You support yourself with affirming self-talk, a healthy lifestyle and a supportive network. You have a sense of humor and an optimistic attitude. Accepting responsibility for your pain, laughter and purpose has strengthened who you are.

Bouncy Challenger (Score from 35 to 74). You have strength in some factors of resilience while other areas need attention. Celebrate what is working and take an inventory of the weaker aspects. Note the answers where you scored 0 or 1. Then develop a plan that will address your resiliency needs. Consider reading articles, books, taking a course and finding reasons to smile more often.

Bouncing Low: (Score from 0 to 34). Please get yourself some help before you become seriously ill, if you are not already. You are at risk for challenges ranging from depression to migraines to irritated bowel syndrome to heart disease. Make a drastic life change, seek help and put a plan in place. By working on your physical, mental and emotional well-being and resilience you will relieve your loved ones of much worry and create the life you deserve. Please see a doctor, confide in a friend or call your local distress centre if you believe you cannot cope. This will be your first step towards rebuilding your resilience.

Note: Although this tool is based on resilience research, neither it nor the scores have been formally validated. It is intended to provide basic information so you might strengthen your resilience.

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For more information, see Patricia Morgan's website:
www.lightheartedconcepts.com

Other resilience assessment tools you may find interesting and helpful include:

- “How Resilient Are You?” by A. Siebert (www.resiliencycenter.com)
- “The Resiliency Quiz” by N. Henderson
(www.resiliency.com/htm/resiliencyquiz.htm)

SHORT-TERM SELF-CARE STRATEGIES

Developing a plan of self-care involves thinking about ways to care for yourself on days when you might feel particularly stressed or worn down. Short-term goals focus on the fast and relatively easy ways that you can soothe yourself and replenish your energy. We call these strategies “the quick wins.” When you get into an airplane, you are often reminded that if there is a drop in pressure, masks drop from the ceiling and you are asked to put your own mask on first before placing the mask on your child. If you don’t care for yourself in the short term, you can’t care for those you love. So even if you feel you don’t have to try these strategies, see them as an experiment. You won’t know what is helpful until you try.

In *An Autism Mom’s Survival Guide (for Dads, Too!)*, Senator (2010) describes several simple activities and products that can be a “quick fix” for immediate help during a tough situation:

- Plunge into a hobby for a moment. Purchasing a small item that is for your hobby can help take you out of the stressful moment and into a better one.
- Go out to a nice dinner with a friend. If this isn’t possible, even making yourself a cup of coffee at home and calling a friend to drink it “with” will provide a nice break.
- Challenge yourself physically. Go for a bike ride or run.
- Do something that stimulates your intellect. Work on a crossword puzzle—exercise your mind.
- Join a club or interest group. You can go to www.meetup.com to find others in your area who enjoy similar things.
- Do something small and quick that makes you feel good about your appearance.
- Indulge in a treat, for example, a piece of chocolate.
- Take a moment to enjoy the beauty of nature. Buy yourself flowers at the supermarket or take a walk in a beautiful spot.
- Put on some music, either a favorite song, or if you play an instrument, take it out to play, even if you think you aren’t in the mood.

Putting on the brakes

Family members have also identified these short-term strategies that helped them ease their anxiety for a moment so they could face their situation with renewed energy:

- Have your morning coffee.
- Talk to someone you trust.
- Hug your pet.
- Take a deep breath.
- Take a time-out.
- Take a long, hot shower.
- Apply your favourite body lotion.

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- Watch your favourite TV show.
- Sit in your backyard after dinner.
- Go for a long walk.
- Become more aware of nature.
- Go to a movie.
- Go shopping and treat yourself to something new.
- Give yourself permission to feel upset and frustrated, and permission to overcome these feelings.
- Structure your day to ensure it includes leisure time.
- Think about things that make you feel happy or soothed or comforted and make a note of them so you can remember to add those things to your list of self-care quick wins.

These short-term strategies will be unique to each family member. List the quick wins that might be most helpful for you, and add to your list when something comes up that you find pleasant or re-energizing.

Rediscovering joy

Whiteman and Roan-Yager (2007) suggest a helpful activity called “Rediscovering what makes you feel joyful.”

Activity 5-2: Rediscovering what makes you feel joyful

Imagine that you are presented with the ultimate gift: three days with nothing to do. You are guaranteed that your children/spouse/job responsibilities and other commitments will be flawlessly handled in your absence. You have nothing to worry about.

- Where would you go to spend your free time? Would you stay home or go elsewhere? Are you mostly planning on staying inside or being outside? (Don't let budget or distance constrain you.)

- You can bring anything you want with you—books, hobbies, music, people or anything you would like. What or who do you want to bring?

- How do you want to spend your time during your three days? What activities or experiences would you like to have?

- What does this fantasy tell you about what you would like to have more of in your life?

Self-care

Getting back to basics

You may face some particularly challenging times when pleasurable activities seem far away or close to impossible. At such times, it is important to ask yourself if your basics are covered:

- Are you sleeping?
- Are you finding time to eat and drink?
- Have you had any fresh air?
- Have you had any basic exercise?
- Is your body working the way it is supposed to?

You know from the close attention you have paid to your family member over the years how critical it is to get proper sleep, and for the body to be working right. If this is an unusually stressful time so that even the basics aren't happening, you need to develop a safety plan for yourself. Keep in mind the airplane analogy and get your air mask on first so you can take care of your family member. This may require getting someone else to help so that you can get five hours of sleep at a time every few nights, asking someone to help you prepare meals on the go, taking a water bottle with you, stocking the car with food and drinks, getting someone to spend some quality time with your other child or children, asking for help with grocery shopping, dishes or laundry so that when you are home, you can get some rest. Even a five-minute hot shower or bath or a 10-minute jog or walk can make a tremendous difference.

Compassion and self-compassion

Another self-care strategy involves recognizing and having appreciation for your own personal strengths. This can take a great deal of practice. We can be very hard on ourselves. We can also start to focus on what we think we are doing wrong, instead of right, particularly where it concerns ill family members. In fact, it can be much harder to watch someone you love in significant distress than to be in that situation yourself. Self-compassion is about taking a gentle approach with yourself in the moment. When we are not able to be compassionate to ourselves, we limit our ability to be compassionate to others.

Acknowledging your strengths and giving yourself permission to be human may involve learning to think in new ways about your circumstances. For example, acknowledging positive aspects about yourself—such as intelligence, a good sense of humour, perseverance, motivation, physical abilities—is particularly important when you are stressed. You can practice this type of thinking every time you become overwhelmed with guilt or hopelessness.

PRACTISING SELF-COMPASSION

Dr. Kristin Neff (www.self-compassion.org) describes self-compassion as involving three processes: Self-kindness, common humanity and mindfulness. Self-kindness means being warm and understanding to yourself when you feel inadequate, feel that you have failed or are struggling. Common humanity means recognizing that being imperfect is normal and that you are influenced by many factors outside of yourself. You are not alone. Mindfulness is described more in an upcoming section, but in this context, it refers to the need for a balanced approach to negative emotions, so that feelings are not suppressed or exaggerated. It involves being aware of our thoughts and feelings, but in a non-judgmental way.

Activity 5-3: Gauge your self-compassion

Dr. Neff suggests asking yourself the following questions to gauge your self-compassion:

- How do you typically react to yourself?
- What types of things do you typically judge and criticize yourself for (appearance, career, relationships, parenting, etc.)?
- What type of language do you use with yourself when you notice some flaw or make a mistake (do you insult yourself, or do you take a more kind and understanding tone)?
- When you are being highly self-critical, how does this make you feel inside?
- When you notice something about yourself you don't like, do you tend to feel cut off from others, or do you feel connected with your fellow humans who are also imperfect?
- What are the consequences of being so hard on yourself? Does it make you more motivated and happy, or discouraged and depressed?
- How do you think you would feel if you could truly love and accept yourself exactly as you are? Does this possibility scare you, give you hope, or both?
- How do you typically react to life difficulties?
- How do you treat yourself when you run into challenges in your life? Do you tend to ignore the fact that you're suffering and focus exclusively on fixing the problem, or do you stop to give yourself care and comfort?
- Do you tend to get carried away by the drama of the situation, so that you make a bigger deal out of it than you need to, or do you tend to keep things in balanced perspective?
- Do you tend to feel cut off from others when things go wrong, with the irrational feeling that everyone else is having a better time of it than you, or do you get in touch with the fact that all humans experience hardship in their lives?

Self-care

A simple self-compassion exercise is to take a moment and apply hand lotion to your own hands. Imagine that your hand is injured and you automatically reach for your hand with your other hand and massage it. Think about how often you take the time to massage your one hand with your other hand when it is not obviously injured. As caregivers, we may automatically jump in and take care of injuries in others. It is equally important for us to jump in and tend to ourselves. Notice how it feels to massage the hand cream into your hands. This is an awareness exercise that you can do every day. In fact, you may even opt to invite your family member with a developmental disability to massage their own hands too. It is attentive and supportive and draws our attention to ourselves in the present moment.

Senator (2010) offers several helpful self-care strategies:

- Yoga, exercise and meditation can be great stress reducers. For research-based information on the benefits of mediation, go to the Mayo Clinic website (mayoclinic.com) and search “meditation.” If you can’t get to a class, you might try an introductory book and audio program, such as *Quiet Mind: A Beginner’s Guide to Meditation*, edited by Susan Piver.
- Consider getting back in touch with you faith or exploring a spiritual tradition you have always been interested in. Many people find comfort and balance in spirituality.
- How you feel about your physical appearance can affect your outlook on life. Neglecting your appearance is the easiest thing to do as a caregiver, especially during stressful times, but for most people, it only makes them feel worse. It’s important to do what you can to make yourself feel better in this department.

Positive self-talk

One way to learn to think about your situation in new ways is through the use of self-talk. For example, tell yourself, “I am doing the very best I can. I’m only human. I am a caring and loving mother.” Letting yourself experience all of your feelings is extremely important when you are coping with difficult circumstances.

Activity 5-4: Quick wins

Strengths

One quick win involves recognizing your strengths. Think about five of your greatest strengths (e.g., the considerate things you do for yourself or for others, your sense of humour, your skill in a particular sport).

List them below.

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____

Role models

Another quick win can involve identifying role models. These could be other people who have overcome adversity in life and whom you admire because of the way they can take care of themselves, both in calm periods and in crises. Think specifically about why you are choosing these particular people as role models, and identify the characteristics that you appreciate in them.

My role models are:

Self-care

Activity 5-5: Stop/start/continue

Think about ways of behaving, feeling or thinking that you would like to:

- stop
- start
- continue.

For example:

I would like to **stop** feeling guilty that I am not doing more for my ill family member.

I would like to **start** taking an afternoon just for myself, to go shopping or to do yoga or to visit with friends.

I would like to **continue** going to a family self-help group such as the Mood Disorders Association of Ontario when this support group ends.

Write down your wishes.

Stop: _____

Start: _____

Continue: _____

LONG-TERM SELF-CARE STRATEGIES

Recognizing and addressing challenges

There are many challenges in having a family member with dual diagnosis. Try to identify and prioritize these challenges. You may decide that some cannot be dealt with quickly or easily. The long-term wear and tear that families can experience can take a long time to develop—and a long time to fix. Many families spend a lot of time dealing with small stressors, working very hard to put out small fires.

Sometimes you can change the problem, and sometimes you need to change the way you think about your relationship to the problem. By thinking about the problem differently, you can cope differently, even if you can't "fix" the problem right now.

Understanding problematic thought patterns

Trying to cope with emotions is challenging for many people at the best of times. When faced with severe and persistent stress, you can find it even harder to deal with anger, grief, loneliness, sadness, shame and guilt.

Remember that feelings are intertwined with thoughts, beliefs and behaviours. For example, if caregivers believe that they caused a family member's disabilities, then they are more likely to feel responsible for their family member's problems. Such beliefs may lead to feelings of sadness, guilt and remorse. If caregivers are not able to cope with these emotions constructively, they might avoid seeking help for their family members or for themselves. This may have serious repercussions for their family members and for their own health and well-being. All the self-care morning coffees in the world will not help if you let problematic thinking rule your thoughts.

In *Feeling Good: The New Mood Therapy*, David Burns (1999) discusses how erroneous thoughts and beliefs may lead to negative emotions. Awareness of the types of problematic thinking often helps caregivers to recognize these types of thinking in themselves. They are then in a better position to work on strategies for changing problematic thoughts and beliefs.

ACCEPTING THE THINGS YOU CANNOT CHANGE

*Grant me the serenity
To accept the things I cannot change;
Courage to change the things I can;
And wisdom to know the difference.*

Self-care

Acceptance is the ability to take in all that a situation offers, without trying to avoid negative experiences (Hayes et al., 1999). Your family will often not be able to control the outcomes of difficult events, but you can make choices and find meaningful ways of participating in the process in which an event will unfold. It is important to look at a difficult situation and identify what elements you can influence and what you can't control, and then focus your best efforts into what is possible to change. In doing so, you can influence the quality of your life and relationships (Walsh, 2006).

One type of psychotherapy that has been proven to help with a variety of psychological problems is acceptance and commitment therapy (ACT). It emphasizes the importance of accepting, and not avoiding, difficult emotions and experiences. Using mindfulness and commitment and behaviour processes to enable greater psychological acceptance, ACT highlights the role of accepting unpleasant emotions in obtaining our personal goals. It has been found to be helpful for families. (Blackledge & Hayes, 2006).

DEALING WITH DIFFICULT EMOTIONS

Various strategies may help you to deal more effectively with difficult feelings:

- Repeat positive affirmations over and over to yourself, such as “I am doing the best that I can and I am a good and decent person.”
- Be aware of yourself and any problematic thoughts you might be having about situations, events and other people that might be resulting in negative feelings. You may not be able to stop these thoughts but, by acknowledging them rather than suppressing them, you may be able to lessen the impact.
- Be aware of how you handle stress and what kinds of stressful situations leave you feeling most vulnerable.
- Develop effective ways of coping with a family member who has dual diagnosis (e.g., find out how to navigate the treatment system and get help).
- Set limits and clear boundaries.
- Talk openly and honestly about how you feel, and examine those feelings, either with someone you trust or within a peer-or professionally-led support group.
- Talk to other families about effective ways to deal with stress and difficult emotions.
- Develop and follow your own personalized self-care plan.

If you practise these strategies on a regular basis, you can cut down the frequency and intensity or the impact of distressing thoughts on your emotions. They can help prevent negative moods from occurring in the first place and can also help prevent them from getting a lot worse. How we feel is determined by what is going on, how we see things and what we are doing physically.

Building social support

Family members often give up their own activities and can become isolated from friends and colleagues when they are caring for a family member with dual diagnosis. But social support is crucial to help you achieve and maintain emotional and even physical health.

Whiteman and Roan-Yager (2007) suggest the following activity to help you figure out what type of support will help you the most.

Activity 5-6: What would help you?

Think about everything that the people in your life could do to be helpful to you. Many people have trouble articulating what would be helpful to them. So, when people ask, “What can I do to help,” many of us choke and say, “I can’t think of anything.” The purpose of this exercise is to help you have a few specific items on your list so that when people ask you what they can do, you have some ready answers.

Here are a few tips about getting the most out of the exercise:

- Remember that you are trying to come up with things that would be helpful to you, not your child. Make sure the primary focus is on you and your needs.
- Don’t edit yourself. Write down everything from your biggest wishes to your smallest wishes. Even if something seems unobtainable right now, feel free to write it down anyway.
- Acknowledge your first thought, for example, “I can’t do anything unless someone takes my child,” and stretch beyond it. Respite is critically important. But it’s only one of many things people can do to help. Be as creative and specific as you can be to get the most out of this exercise.

Continued on next page

Self-care

Questions

What can others do to support you emotionally? Call you? Come over and watch the hockey game with you? Bring you an ice cream sundae? What would make you feel great?

What can others do to help you with the practical realities of life?

What can others do to help support your life goals and objectives? Be as out there as you want.

What do you find the least helpful to you? For example, it really bothers you when people say, “It is just so awful” (no pity parties) or when people try to offer problem-solving support (trying to fix it for you) when what you need is validation.

FRIENDS AND COLLEAGUES

Some people find it very helpful to have a large social network to draw on. Others prefer to have only a few supportive and understanding friends. Participating in a group activity you enjoy, such as a walking club, sports team, reading club or church group, can help you retain your social network. Old friends and colleagues you’ve grown apart from may appreciate hearing from you. Being open about your situation will often bring support from the least likely places and people.

INFORMAL SELF-HELP ORGANIZATIONS

Support groups can help create a community where many issues can be freely discussed. Joining a support group can help remind you that you aren’t alone in your daily struggles. However, it is important to choose a support group that best fits your needs. There are large groups and small ones, ones that meet weekly, and others that meet monthly. There is no one right way to have a support group; however, it’s important to find the right one for you (Tilton, 2004).

You can find helpful information about local support groups in your area through:

- **Community Living Ontario:** www.communitylivingontario.ca
- **Developmental Services Ontario:** www.dsontario.ca (for information about groups in your region)
- **Extend-a-Family:** www.extendafamily.ca
- **Family Alliance:** www.family-alliance.com

Some groups are focused on specific disabilities or specific cultural groups:

- **Autism Ontario:** www.autismontario.com
- **Fetal Alcohol Spectrum Disorder Ontario Network of Expertise support groups:** www.fasdontario.ca/cms/resources/support-groups
- **Heep Chi Association:** www.heepchi.com
- **South Asian Autism Awareness Centre:** www.saaac.org

These regional support groups and family resources may also be helpful:

- **Ensemble:** www.ensembleunderstands.com (southwestern Ontario)
- **United Families of Eastern Ontario:** www.ufeo.ca (eastern Ontario)
- **Youthlink Parent Group:** www.youthlink.ca
- **The Care to Know Centre:** www.caretoknow.org

BUILDING A SELF-CARE PLAN

Developing a self-care plan will help you think about the small steps you can take in your own life to build resilience and reduce your vulnerability to compassion fatigue.

Imagine what your self-care plan might look like. This plan should address all your needs:

- **biological:** caring for your own physical health
- **psychological:** taking care of your emotional health
- **social:** taking care of your social needs and networks
- **spiritual:** drawing on sources of spiritual help that might comfort and guide you.

This plan is called the biopsychosocial-spiritual self-care plan. Just remember to be very specific in developing your self-care plan. For example, a family member may choose to include something like the following in their plan:

- I will work out at the local gym three times a week for 30 minutes each time.
- I will walk reasonable distances instead of taking my car.
- I will go to Pilates classes with my friend Sheila once every week.
- I will eat three fruits a day and take a B6 multivitamin.
- I will prepare two meatless dinners a week.

Self-care

Activity 5-7: Self-care plan

Think about how you can take care of your needs. See the following example of a self-care plan:

BIOPSYCHOSOCIAL-SPIRITUAL SELF-CARE PLAN	
Physical health	Emotional health
<ul style="list-style-type: none"> • start daily walks again • return to exercise classes (30 minutes low impact at first; when ready, 45 minutes of high impact + weights) • park my car further away from entrances and walk the remaining distance • use stairs instead of escalators • start shopping for healthy foods that I enjoy and return to healthy eating habits. 	<ul style="list-style-type: none"> • attend family support groups with my husband to help us cope with Kevin's illness • resume my gardening • set limits with Kevin (e.g., practise saying no, allow him to make mistakes) • talk to my husband about stresses instead of having a drink after work • continue attending support group monthly meetings • daily quiet time by myself to read, garden or write in my journal.
Social life	Spiritual life
<ul style="list-style-type: none"> • go out for dinner with husband at least once a month • resume Friday "euchre nights" with our closest friends, Martha & Harry when possible • go out with my best friend, Sue, at least once per month (shopping/ lunch) • resume "family weekend outings" on Sundays. 	<ul style="list-style-type: none"> • take classes on how to meditate • increase awareness of nature (e.g., birds & flowers during day, stars & solitude at night) • return to my readings on Buddhism & serenity • do my yoga sessions every morning when things are quieter around the house • return to my daily meditation readings.

Now write down your ideas so you can take care of your needs.

BIOPSYCHOSOCIAL-SPIRITUAL SELF-CARE PLAN	
Physical health	Emotional health
Social life	Spiritual life

Self-care

If one of the areas in your self-care plan looks sparse or empty, you may want to think about whether this is a component of your life that you should work toward expanding. For example, if you have always been an energetic and active person, and in your personal impact log (from Chapter 4) you wrote down that you are too busy to exercise and that you feel down and tired all the time, this is an excellent area in which to begin working on your own health and well-being.

Becoming informed

Information is power. Many family members seek both formal and informal opportunities to learn about dual diagnosis. They find it helpful to learn as much as they can about the particular issues that the person with dual diagnosis is experiencing, including the causes, signs, symptoms and possible treatments.

Believing in yourself and your rights

You have a right to ask questions and to receive attention and respect from health care professionals. Some people with dual diagnosis want their family members to be very involved in their treatment plan, even if they're in hospital. Others may prefer not to involve their families and may want to keep their personal information confidential. Whether or not you are actively involved in the professional care of your family member, you have a right to:

- your own support from health care professionals
- education about mental illness and developmental disability
- information about the latest research and most effective treatment options
- respect and validation.

Advocating for change

Stigma, which involves negative attitudes and behaviour toward people with developmental disabilities and mental health problems, has powerful effects that people can't easily overcome on their own. Stigma can prevent legislators from setting aside enough money for mental health care and financial support for caregivers; it can keep insurance companies from providing enough coverage.

For many family members, educating others about the myths, stereotypes and realities of dual diagnosis is an important way to reduce stigma. Families have worked hard to decrease irrational fears while attempting to humanize and promote acceptance of both the people with these disorders and their families. Family members have recognized that health care workers, education professionals and the media need to be educated as well.

Family groups are one of the best catalysts for change. Members of family self-help support groups can:

- argue for better treatment, planning and accountability
- sponsor conferences
- speak at professional meetings
- lobby legislators and appointed officials.

The family movement has significantly influenced research and treatment for people with dual diagnosis. Family members have developed effective relationships with researchers, mental health professionals, legislators and administrators without compromising their own independence as advocates.

You can find helpful information on dual diagnosis advocacy through the Canadian Association for Research and Education in Intellectual Disabilities (CARE-ID) website. This site also has fact sheets that can be useful when discussing issues with policy makers or media.

Advocacy tips

1. Be well informed.

As a family member or friend of a person with dual diagnosis, you already know the effects of this condition. Your experience and knowledge are some of the greatest tools you can bring to your advocacy efforts.

2. Identify your issues.

You may have many areas of concern (e.g., access to comprehensive dual diagnosis screening and assessment, access to integrated treatment), but it is best to keep your communication targeted. Focus on one or two issues at a time.

3. Communicate effectively with government officials.

Connect with officials, either in person or by phone, to expand relationships and present your key messages. You can call your local member of Parliament (MP) and review your key issues. If you are able to speak directly with your MP, be specific, persuasive and factual. Keep your conversation short. Make sure you thank the official for his or her time. Finally, follow up with a brief letter reinforcing your key messages. If you cannot speak directly with your MP, leave a message with their assistant. Be sure you know what you want to say, say it politely and don't forget to leave your name, address and phone number.

Self-care

Send a letter to a federal government ministry such as Health Canada or Justice Canada. Letters, either through Canada Post or e-mail, are powerful ways to get key messages to MPs. When writing a letter, remember to use the correct address, use your own words and personal experiences, identify the issues and key messages and don't forget to say thank you. Letters are a great way for politicians to get to know the real faces of people with developmental disabilities affected by mental health problems. You are critical to making this happen.

Here are some suggestions for preparing to communicate with government officials:

Find your federal MP by entering your postal code at: www.parl.gc.ca/information/about/people/house/PostalCode.asp?lang=E&source=sm.

You can find out about the federal ministries and the ministers responsible for each ministry at www.parl.gc.ca/information/about/related/Federal/Agency.asp?Language=E&Agency=M.

4. Communicate effectively with the media.

Your local newspaper, television or radio station may be willing to write an article about your experiences and key issues. Again, it is important to be clear and concise when speaking to the media. Be prepared when you speak to a journalist and remember to stick to your key messages. You may also want to contact local, provincial, territorial or national organizations for more information before speaking with the media.

Adapted with permission from Advocacy Tips (Schizophrenia Society of Canada)

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Navigating the treatment system

6

Outline

- Is there a system?
- What should happen: Integrated treatment
- Access points
- Assessment and diagnosis
- Treatment planning
- Treatment approaches
- Co-ordinating treatment
- Hospitalization
- Continuing care

IS THERE A SYSTEM?

There are many services for people with developmental disabilities and many mental health resources and services for the general population, but what is sometimes missing are the threads to join these resources and services together. If those threads were in place, then roles and tasks would be clearly understood, client-centred planning started and services across programs easily accessed. Connecting services is even more of a concern when clients have complex problems, which is usually the case for people with dual diagnosis. Although health care and social service providers will acknowledge that a client has many needs, too often they aren't willing or able to say, "You've come to the right place, and we are the right people to work with you. If we can't meet all of your needs, we have access to other resources that can."

WHAT SHOULD HAPPEN: INTEGRATED TREATMENT

Treatment works best if the client and the client's caregivers (e.g., family members) have one contact person who is responsible for co-ordinating different aspects of care. Ideally, this relationship should be long-term, stable and trusting. An integrated approach to care may include someone with more expertise in mental health and others with more expertise with developmental disability, but these people should work together to meet all the needs of the client and their family.

Most integrated programs have been developed for clients who have the most severe mental health problems or who have had several failed attempts at accessing mental health services and who also struggle with their social services. Integrated programs have common features, including:

- interdisciplinary teams
- capacity building of caregivers
- emphasis on behaviour.

If integrated care always required that clients be served in a single program, current service systems would have to be completely rebuilt. Fortunately, developmental and mental health service providers are discovering that many people with dual diagnosis can receive well-integrated care from different programs if:

- links are established among programs
- one person or team takes overall responsibility for ensuring that services are co-ordinated.

Many developmental disability and mental health service providers have forged collaborative relationships that allow them to offer integrated approaches to treating dual diagnosis.

ACCESS POINTS

Finding a program that is a good fit for your family member with dual diagnosis can be a challenge for several reasons:

- Many communities do not have a specialized integrated dual diagnosis services to assess and treat complex cases.
- In some communities, the waiting lists for specialized services are too long.
- Developmental disability programs or mental health programs and services may have admission criteria that exclude clients with dual diagnosis.
- Finding psychiatrists or clinical psychologists who can provide psychiatric diagnoses to people with developmental disabilities can be a challenge in many communities.
- Treatment resources may be lacking, even though you, your family member with dual diagnosis or your doctor understand what would be most helpful.

But you have to start somewhere, so we will begin by discussing the most common entry points into the system.

Developmental disability agencies

Many developmental disability agencies accept self-referrals or referrals from families. After an initial intake assessment, the person will be referred to the most appropriate service for their needs. This may include behavioural therapy, counselling and speech and language or psychological assessments to better understand the disability. Some agencies provide only one or two types of services. If the problems seem particularly complex, these agencies may make a referral to a specialized dual diagnosis service provider.

In Ontario, the Ministry of Community and Social Services and the Ministry of Children and Youth Services fund services in the community, often called “the developmental sector.” The developmental sector can include in-home and out-of-home respite, employment programs and other day activities and residential services.

In July 2011, Ontario introduced centralized access to developmental disability services for people age 16 and older through [Developmental Services Ontario \(DSO\)](#). In the past, families would need to call many different providers to get all the services they needed. The DSOs serve as the single door to services in any region. Someone at the DSO can usually give you information on what services are available and the process you must follow to obtain such services. There are nine DSO regional offices across Ontario. You can find out more information, including where your local DSO office is located, at www.dsontario.ca.

Community mental health agencies

Every region of Ontario has community mental health agencies. You can find information about them in the ConnexOntario Mental Health Helpline online directory. These agencies provide case management, as well as counselling, some group therapy and nursing and psychiatric support. They may also have recreational and vocational programs for people with mental health problems. These services are not designed specifically for people with dual diagnosis, but some people, particularly those with milder disabilities, can benefit. Services and supports may also be helpful to other family members. In some areas of Ontario, community mental health agencies offer dual diagnosis supports and services.

In Ontario, the Ministry of Health and Long-Term Care funds general health services, such as medical assessments and hospital-based services. It also funds the assessment and treatment of mental health problems through psychiatric emergency treatment, outpatient mental health clinics, acute-stay hospital beds, extended residential care and assertive community outreach teams.

ConnexOntario

ConnexOntario is a bilingual information and referral service in Ontario for the public and professionals wanting to access mental health or addictions treatment for themselves, family, friends or clients. Information and referral specialists offer education and guidance based on each caller's situation. They have specific information on mental health agencies that provide services to people with dual diagnosis. They do not have information on developmental disability services available through the Ministry of Community and Social Services. When you call, it is important to mention dual diagnosis.

Toll-free telephone numbers:

Drug & Alcohol Helpline: 1 800 565-8603

Mental Health Helpline: 1 866 531-2600

Ontario Problem Gambling Helpline: 1 888 230-3505

These information lines are available 24 hours a day, seven days a week. You can find more information about ConnexOntario at www.connexontario.ca.

Psychiatrists

A referral from a doctor is almost always needed before a person can see a psychiatrist. Family doctors often have a list of psychiatrists to whom they can make referrals, but the lists may not include psychiatrists with expertise in dual diagnosis.

Your family member may have to wait at least two to three months to see a psychiatrist. After the appointment, if you or your family member don't agree with the diagnosis, ask your family doctor for a referral to another psychiatrist for a second opinion. Most doctors are open to their patients seeking another perspective and may even suggest it.

Dual diagnosis programs

There are some specialized programs where clinicians have expertise in both developmental disabilities and mental health problems. Typically, these programs are interdisciplinary, meaning that clinicians, such as psychiatrists, psychologists, behaviour therapists, nurses, occupational therapists or social workers, work together to figure out what the problem is and how to best treat it. These programs can have long waiting lists, but they are appropriate when other more general services cannot meet your needs. To learn more about specialized services in your area in Ontario, you should start by speaking with someone from your local Developmental Services Ontario office. In addition, you might be able to get some information about services by contacting the Community Networks of Specialized Care. The CNSC co-ordinators and health facilitators can direct families to available services and can explain how to access them.

Community Networks of Specialized Care (CNSCs)

The CNSCs were created to enhance service to adults with a developmental disability who need specialized care for co-existing mental health and/or behavioural issues. They ensure a system that is:

- accessible—so that people and their caregivers/families can access the clinical services they need, when and where they need them
- co-ordinated and integrated—so that services and supports from a number of programs, organization and sectors work together with people and their families to make a difference
- accountable—to ensure networks are actually making a difference.

For more information about the CNSC in your area, visit www.community-networks.ca.

Navigating the treatment system

Primary care

Primary care providers (e.g., family doctors, nurse practitioners, family health teams) are often the first professionals that people talk to about a mental health problem. They can examine your family member's physical health and rule out problems that could be adding to or affecting changes in their mood, thinking or behaviour. Sometimes primary care providers can do a full psychiatric assessment, particularly for the more common conditions, such as depression or anxiety. Sometimes, they will suggest that a person see a psychiatrist.

Primary Care of Adults with Developmental Disabilities, a set of guidelines developed for primary care provider and published in *Canadian Family Physician*, is available on the Surrey Place Centre website. The Behavioral and Mental Health section of the guidelines is particularly relevant to dual diagnosis. The website also includes a collection of tools that primary care providers can use when they are working with patients with developmental disabilities.

Hospital emergency departments

In a crisis, you and your family member can go to the emergency department of a hospital. If the situation does not require immediate medical care, the next step may be a more in-depth assessment from a crisis worker. This person is often a nurse or social worker. Your family member may also have an assessment by a psychiatrist. Sometimes visits result in hospital admission; other times, recommendations are made and you and your family member will return home. For detailed information on hospitals and emergency departments, see the section in this guide called "Hospitalization" (p. 91) and "Getting treatment in an emergency" (p. 121).

ASSESSMENT AND DIAGNOSIS

CAPACITY TO CONSENT TO TREATMENT

In Ontario, everyone has the right to make decisions about their treatment if they are mentally capable to do so. This includes refusing treatment.

To be considered capable, a person must:

- be competent to give consent
- have the intellectual capacity to make the decision
- give the consent voluntarily
- have enough information to make an informed decision, including information on potential risks or side-effects of treatment.

If the person is not able to give informed consent, they must be declared incompetent. Someone is appointed to make decisions on their behalf. In some provinces and territories, the decision-maker is a family member; other provinces use people appointed by the state. In Ontario it is the Public Guardian and Trustee (www.attorneygeneral.jus.gov.on.ca/english/family/pgt/).

Just because your family member has a dual diagnosis does not automatically give other family members the right to make decisions for them. Whether your family member with dual diagnosis can make his or her own decision depends on the decision to be made and how he or she is doing at the time. Some decisions are more complicated than others; for example, agreeing to a high-risk medication regimen is a more complicated decision than agreeing to participate in a counselling session. Some adults with dual diagnosis are able to make informed decisions when they are feeling well, but when they are not feeling well, they lose that capacity.

If you have concerns about whether your family member can make decisions around mental health treatment, particularly in emergency situations, it can be worthwhile to talk about this with your care team before an emergency arises.

Assessment

Assessments usually start with a conversation with the health care provider.

Questionnaires are often part of the assessment interview. The treatment provider investigates medical, environmental and psychological contributors to the current difficulties. During an assessment, people are often asked to discuss things such as:

- why they have come for help, what kind of help they are looking for and what has helped in the past
- their physical condition and any new or ongoing medical issues. Some people with developmental disabilities have difficulty reporting pain and we only notice that they are in pain because of their “difficult behaviour.” Therefore, it is very important to know how your family member reports pain.
- general life problems, troubling thoughts or feelings, substance use problems and how long problems have lasted
- whether they have experienced trauma (e.g., physical or sexual assault, war), even if it occurred years before
- whether there is a history of mental health problems and/or developmental disabilities in their family
- what their life is like (e.g., how they feel, what they think, how they sleep, if they exercise and socialize, how they do at school or work, how their relationships with friends and family are, loss in their life)
- whether they have come to Canada in the last few years and/or whether they have come from a war-torn country
- what, if any, medications they take.

The client and the treatment provider use the information from the assessment to develop a treatment plan. Some of these issues are addressed in the [Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities](#). In *There are No Quick Fixes*, Yona Lunsky describes the process of determining whether a person has a mental health problem.

There are ways to help prepare for this kind of assessment:

1. Bring copies of past assessments.
2. Bring information on past treatments, including medications.
3. Complete your portion of the [Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities](#) tool to share with your doctor and psychiatrist.

Diagnosis

It is usually, but not always, necessary to have a formal diagnosis of developmental disability to access services. In Ontario, most services offered by the developmental sector require a diagnosis of developmental disability. The Developmental Services Ontario office must confirm that an applicant is eligible, according to the Ontario definition before any services can be pursued. In a crisis situation, action may need to happen before the diagnosis is confirmed. Keep in mind that understanding the degree of disability and the level of supports required is an important aspect of treatment planning. A proper psychiatric diagnosis relies on understanding the person's cognitive and adaptive limitations and strengths.

It is not always necessary to have a psychiatric diagnosis before starting mental health treatment. However, a diagnosis may help to direct treatment. For example, a diagnosis may determine whether a particular kind of therapy would be most helpful and whether there are medications that could help to treat the problem.

Even if your family member does receive a preliminary psychiatric diagnosis, it may change or be interpreted differently by other health care providers over the course of treatment. It is often hard to determine whether symptoms are related to a mental health problem, a medical issue or the current environment. The only way to figure out what you are dealing with is to see how the symptoms develop over time.

TREATMENT PLANNING

There is no single, correct intervention or program for people with dual diagnosis. The treatment plan needs to be customized to address each client's particular needs. Treatment plans should:

- identify issues and problems
- outline short-term and long-term goals
- establish approaches and interventions to meet the goals.

In many cases, treatment includes helping your family member with employment, housing, finances, leisure activities and basic daily self-care. The person giving the assessment may recommend that your family member see a therapist or that they start taking medication. Sometimes, the treatment is about adjusting our supports and expectations of the person with the disability, as opposed to just treating the person. Often we don't recognize how much support a person really requires. When we adjust our approach, there may be noticeable improvements in behaviour.

Family involvement

Families typically provide ongoing, day-to-day care, so they should be involved in treatment planning if possible. Families will often have information that should be considered by the treatment team as part of the planning process. Your perspective may be different than that of your family member or the treatment team. The Caregiver Health Assessment tool helps you collect and record treatment-related information.

The amount of family participation will depend on your family member. One barrier to family involvement that treatment providers and families identify is unclear confidentiality policies. A treatment provider cannot share case-specific information with you without your family member's agreement unless you are the substitute decision-maker.

Many parents assume that they make the decisions for their child, but in Ontario, it is assumed that the person, even if they have a disability, can make their own decisions, unless demonstrated otherwise. Sometimes families assume that the paid caregivers can make decisions for their family member. This is never the case. Paid caregivers can make certain treatment decisions on behalf of the substitute decision-maker only when there is formal communication between the paid caregiver, health care provider and substitute decision maker (see *Capacity to Consent to Treatment* p. 81).

Treatment providers should ask clients if they agree to have family members participate in planning and treatment. However, many treatment providers don't ask, so it's best to talk to your family member and let the treatment team know what you have agreed to. Have this agreement added to your family member's treatment record. If more than one agency is involved in care, make sure each one is aware of whether your family member has agreed to share information with you and has a copy of that agreement in its files. You may need to start the conversation because each agency may assume that the other has talked to your family member. You can use the [Informed Consent in Adults with Developmental Disabilities tool](#).

Learning about dual diagnosis will help you to recognize what type of information will be useful to the treatment team. It often helps to organize your questions and concerns into a document. Keep the document short and to the point, and keep the tone neutral. If possible, you and your family member with dual diagnosis should work together to decide what information to include. Consider completing the patient/caregiver sections in the Today's Visit form before the appointment and ask the clinician to fill in the physician / nurses section at the end of the appointment. You can keep a copy of the form in a binder with other information on assessments and consultations.

IF YOUR FAMILY MEMBER DOES NOT WANT YOU INVOLVED

Even if your family member hasn't agreed to share treatment information with you, the treatment team can still talk to you about:

- the nature of developmental disability and mental health problems
- how to respond to disturbing behaviours
- how to get help in an emergency
- how to get help for yourself.

The treatment provider can also listen to your observations. Avoid making treatment recommendations—remember, you are not the attending physician or psychiatrist—but allow the treatment team to draw conclusions from the information you present.

If your family member doesn't want you to be involved and wants to make their own health care decisions, check periodically to see if they have reconsidered or to express that you would like to be more involved.

Questions to ask about the treatment plan

If your family member has agreed to have you involved, here are some questions to ask about their treatment plan:

- What is the provisional (initial) diagnosis?
- What are the possible causes of my family member's problems?
- What is the proposed treatment?
- What are the benefits and risks of the treatment?
- Are other treatments available?
- What are the options if this treatment doesn't work?

TREATMENT APPROACHES

Treatment for dual diagnosis includes psychosocial treatments (discussed in this chapter) and medication (see Chapter 7). Psychotherapy can be either short-term or long-term.

Individual therapy allows the therapist to focus solely on the client, with no distraction from others. When someone with a developmental disability has individual therapy, family or paid caregivers may still be involved at the start or end of the session, particularly to help the person to complete homework and practice skills learned in the session. It can be very empowering for a person with a developmental disability to have one-to-one time with a therapist.

Group therapy (groups led by professionals) offers the advantage of promoting social support among clients and allowing them to learn from one another. Groups usually consist of up to 10 people. Often two therapists run them. A group setting can be a comfortable place to discuss issues such as family relationships or medication side-effects. Groups are also an excellent opportunity for people with developmental disability to practice social skills. Some groups for people with developmental disability might include caregivers or offer a parallel group for families.

The types of therapy described below may be provided to those with a dual diagnosis but can also be useful to educate family members.

PSYCHOEDUCATION

Psychoeducation is education about mental health problems. People who know about their problems are better prepared to make informed choices. Knowledge can help clients and their families deal with their problems and make plans to prevent future problems.

Psychoeducation sessions include discussions about:

- what causes mental health problems
- how the problems might be treated
- how to self-manage the problems (if possible)
- how to prevent future episodes.

PSYCHOTHERAPY

Psychotherapy is sometimes called “talk therapy.” It helps people deal with their problems by looking at how they think, act and interact with others. There are many different types of psychotherapy.

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Behaviour therapy

Behaviour therapy focuses on changing a person's behaviours for the better. It teaches people how to be aware of why they behave in specific ways and teaches new behaviours that can replace problematic ones. It involves looking at what purpose a behaviour serves and the types of reinforcement that are instrumental in learning. There is a substantial amount of research showing that behaviour therapy can be helpful for people with dual diagnosis.

Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) is based on the theory that thoughts have an important influence on how people behave. Therapists help clients to identify unhelpful thoughts and behaviours and learn healthier skills and habits. The client and therapist identify goals and strategies. There is an emphasis on practicing the skills between sessions (homework). A growing body of research demonstrates that CBT can be helpful for people with dual diagnosis who have the language skills necessary to participate in talk therapy.

Social skills training

Social skills training uses techniques such as role playing, modeling, coaching, homework and feedback to help people learn (or relearn) interpersonal skills and competencies. Social skills training can teach people with dual diagnosis more helpful ways of relating to others.

Dialectical behaviour therapy

Dialectical behaviour therapy (DBT) is a type of cognitive-behavioural therapy. It is used to treat a range of behaviour problems. In DBT, people look at how their background and their life experiences affect how they control their emotions. DBT draws on western cognitive-behavioural techniques and eastern Zen philosophies. It teaches clients how to:

- become more aware of their thoughts and actions (“mindfulness”)
- tolerate distress
- manage their emotions
- get better at communicating with others
- improve their relationships with other people.

Psychodynamic (or insight-oriented) therapy

Psychodynamic psychotherapy, also referred to as insight-oriented therapy, is based on the theory that unconscious processes (issues that a person may not be aware of) influence behaviour. This approach helps people examine unresolved issues that have resulted from relationship problems in their past. There is not much evidence for the effectiveness of psychodynamic therapy for people with dual diagnosis, although in some specific cases it may be a part of treatment.

Other less language-based therapies

Other forms of therapy that rely less on language have been adopted with people with developmental disabilities. These include play therapy, sand therapy, music therapy and art therapy. Therapies can focus on sensory experience and provide new ways to increase distress tolerance and offer creative opportunities to express emotions and have a reciprocal exchange with another person. These therapies can also help clients to build self-esteem and develop new, more adaptive ways of coping with stress.

Peer support groups

A peer support group is a group of people with similar problems. Group members can share their struggles in a safe, supportive environment. Group members usually develop strong bonds.

There are peer support groups for clients with very mild developmental disabilities and mental health issues. There are also groups for families. Although these groups are often called *self-help*, peer support actually offers a type of help called *mutual aid*.

Tips for evaluating peer support groups

Most family self-help/mutual aid organizations are geared toward either mental health issues (e.g., Mood Disorders Association of Ontario) or developmental disabilities (e.g., Family Alliance of Ontario). However, many family members of people with dual diagnosis have found either or both types of groups to be very helpful. There are some groups specific to dual diagnosis, such as Concerned Parents of Toronto Inc.

If you are interested in a group, it is a good idea to evaluate it in order to decide whether it suits you and your situation.

Questions to ask about a self-help group

- Does this group welcome new members?
- Do group members respect one another?
- Is the group relevant to my situation, concerns and needs?
- Are there any requirements for attending this group (e.g., a membership fee)?
- Is the group respectful and inclusive of not just family members from diverse backgrounds (e.g., from a range of cultural, racial, religious and economic backgrounds)?

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- Does the group offer both support and education?
- Is the group ongoing or is it time-limited?
- Does the group have a positive attitude toward professional help for families?
- Who facilitates the group and how is the group process managed?

Therapy for family members

Family members can also enter care as clients themselves. Family therapy can offer advice and support to family members and teach them:

- about dual diagnosis
- how to help the client and support treatment efforts
- how to care for themselves.

Usually, therapists work with one family at a time. Sometimes, family therapy is offered in a group setting with other families in similar situations. Group members can share feelings and experiences with other families who understand and support them.

CO-ORDINATING TREATMENT

Case management

People with dual diagnosis may go to a community mental health agency for case management (these case managers have expertise in mental health but not developmental disability) or to a developmental service agency (these case managers have expertise in developmental disability but not mental health).

There are also some case managers with expertise in dual diagnosis. In Ontario, if your family member needs case management and you are trying to decide how to pursue this, think about the kinds of services you want to access and how familiar you want the case manager to be with developmental disabilities. If your family member has significant mental health and developmental issues and you think you need help to co-ordinate care that goes beyond standard case management but don't know where to start, you can contact the co-ordinator of your region of the Community Networks of Specialized Care (www.community-networks.ca).

Assertive community treatment teams

Some people with severe mental health issues can access more intensive community supports known as assertive community treatment (ACT) teams. These teams do support some people with dual diagnosis, as long as the psychiatric issue is a disorder like schizophrenia, other psychotic disorders or bipolar disorder. More details about the criteria are available in the [Ontario Program Standards for ACT Teams](#).

The ACT model was developed to meet the needs of clients with severe mental illness who often experienced relapse and re-hospitalization, often due to their inability or unwillingness to go to local mental health agencies. The ACT team provides around-the-clock support and services, such as case management, assessment, psychiatric care, employment and housing assistance, family support and education, substance abuse treatment and other services that help a person to live in the community.

HOSPITALIZATION

Sometimes a time-limited inpatient admission is warranted. The decision to admit someone to a hospital for a behavioural or psychiatric issue is usually made by a psychiatrist. Typically, this decision is made at the hospital emergency department, following a psychiatric assessment.

Sometimes an admission to hospital is planned when the person is an outpatient, for various reasons:

- The person may require very close observation.
- It might be important to see the person outside of their current environment.
- There may be complex medical issues that need to be addressed in a hospital setting.
- There may be a need to adjust medications in a very safe and controlled setting.

There are various advantages to a planned admission:

- The person and family can prepare for the admission.
- There is a shared understanding of why the admission is taking place.
- The hospital can prepare the space for the person's unique needs.

Hospitalization can be very stressful for someone with a developmental disability and is not a decision that is made lightly. The team considers the risks and benefits to hospitalization. If it is the safest way to conduct an assessment or initiate treatment, the person may be hospitalized, even though it will cause them stress.

Navigating the treatment system

Planning a hospital stay

There are various ways in which families can help to make hospitalization less stressful for someone with dual diagnosis.

VISIT BEFORE ADMISSION

When possible, it is helpful for families to visit the hospital unit before admission. It can also be helpful for your family member to visit the hospital or to see pictures of it and the room in which they will be staying. Hospitals have many rules, so it is good to learn them. You may want to ask:

- When can visits happen?
- What can families bring in to hospital?
- When can my family member leave the hospital?
- Who do I call if I have a question?
- Are any types of restraints used in the hospital, and if so, what are the procedures involved and will I be contacted if restraints are used?

It is very important for your family member to get to know who their staff will be. Learning names can be hard, so it might be a good idea to post the names of staff, along with photos of them, if possible, on the wall. It can also be helpful to post a description of what jobs staff do; for example, “Joan is my nurse. I talk with her about taking medication, eating my meals and the activities I do during the day. Dr. Lee is my doctor. She will ask me questions about how I am feeling and try changing the medication that I take to a medication that will make me feel less tired.”

INTRODUCING HOSPITAL STAFF TO YOUR FAMILY MEMBER

Moving from the community to a hospital is a major change in routine that can be very hard for people with developmental disabilities. Tell hospital staff about your family member’s existing routines, including the times of day that certain things happen and the days of the week that certain activities occur. Knowing these routines, even if they can’t be followed in the hospital, can help to prepare staff to better support your family member. For example, Wednesdays may be a very exciting day for your family member because that’s the day they go bowling. Even if bowling is not an option in the hospital, knowing the importance of Wednesdays to the patient is important for staff. If your family member always gets dressed in a particular order or always gets dressed after breakfast, this is good information to give to nursing staff.

Consider whether there are any community-based activities or programs that could be kept up while your family member is in the hospital. It is stressful and disruptive to have to miss out on community involvement.

Describe to staff any unique language or phrases that your family member uses which staff may not understand or appreciate. Let staff know how your family member would relay that they are in pain, upset or agitated. Explain how you respond in those situations to prevent the agitation from increasing. The [hospital passport](#) is a useful way to introduce your family member to hospital staff and can be kept at the nursing station or by your family member's bed.

BRINGING COMFORTS FROM HOME TO THE HOSPITAL

Decide with your family member and hospital staff what would be safe to bring to the hospital and what would make your family member's stay feel more home-like or familiar. This may mean putting photos on the wall of their hospital room or bringing comfortable clothes, music, games or activities, a favourite pillow or blanket. We all need ways to soothe ourselves. Your family member may have particular music or activities that they enjoy when they feel stressed. Just be sure that they can manage if these comfort items get lost or destroyed.

SAFETY

Hospitals have well-documented policies and procedures to protect patients and staff from risk. For example, all new clients admitted to an inpatient unit are assessed for their risk for falling. The treatment plan then incorporates prevention and safety precautions if necessary.

Medication reconciliation also happens before a patient is admitted to the hospital. This means that medications prescribed outside of hospital are thoroughly reviewed by the inpatient service to make sure that important medications are not changed unintentionally.

In a planned admission, the behaviours of a person with a dual diagnosis may also be assessed prior to admission. Strategies that have previously worked may be incorporated into the treatment plan.

Family involvement during stay

How much family involvement in the hospital occurs will vary by family and individual. This is a discussion that is very important to have with the hospital team. Predictability is very important. Discuss how often visits take place and for how long. It is most important that once these decisions are made, they remain consistent. Write down a schedule of visits and phone calls for your family member to see. It can be particularly frustrating for them to call you at a scheduled time and get no answer. But if staff members know that a phone call will happen at a certain time, they can help reduce to your family member's anxiety around that time.

Navigating the treatment system

Families can also stay involved with their family member's care by attending staff meetings. Find out when the team will meet to review your family member's case and see if you can attend to give information.

Part of family involvement during a hospital stay is also preparing for discharge. Family and community staff who will be involved with your family member after they leave the hospital should spend time on the unit, learning routines and best ways to respond so that the approach to care can be consistent following discharge.

CONTINUING CARE

People with dual diagnosis should have a team of resource workers who take an ongoing, respectful and proactive interest in supporting them and their families. Continuing care does not necessarily mean that the client and counsellor must continue to meet regularly; it means that from the counsellor's perspective, the client is always welcome, even if the last contact was some time ago.

Because dual diagnosis is complex, there may be many transitions in the care process (e.g., between inpatient and outpatient care, between outpatient treatment and community care with the family doctor only). Treatment providers should take responsibility for managing the transition and for following up to ensure that the new arrangement works. However, we know that this co-ordination is sometimes left to the family.

Transition or discharge planning should begin when your family member enters care. You and your family member need to be involved. Make sure that the treatment team understands how much care you can provide and that services are put in place to fill any gaps. A transition plan should include a full array of services, including:

- case management
- financial support
- housing
- physical health needs
- support networks.

When your family member leaves treatment, you need to be clear about how to reconnect with the service, if necessary.

Questions to ask about a transition or discharge plan from hospital

- Has a follow-up session been scheduled? (If so, make sure you know the date and time, location, contact name and telephone number.)
- What medications have been prescribed? What are they for? What is the dosage of each prescription? When should the medication be taken? Will there be a few days' supply given by the hospital, for before the prescription is filled?

If your family member isn't living with you:

- What arrangements have been made for housing?
- Have resources been identified to help your family member become involved in meaningful daytime activities?

It takes a lot of effort and commitment to make the mental health and developmental services systems work for your family member. You should be recognized as a partner in organizing and delivering the care they need, so educate yourself about dual diagnosis and treatment options, be persistent, ask questions—and keep asking them until you get the information you need.

Team meetings

It can be very helpful to continue to hold team meetings even when things seem to be going well. It is important to take notes about decisions made and to share these notes with the treatment team.

For any team meeting, it is important to consider whether to involve your family member with dual diagnosis. Sometimes too much talking about their difficulties is stressful and they would prefer not to be present. This is a decision that the team can make together, with the input of your family member.

Often team meetings include the family member, their family and support providers, but no medical professionals. This may happen because these professionals have busy schedules or believe that dealing with behaviour and support issues should not be the concern of health care providers. However, holding meetings without a medical professional makes it hard to integrate medical and behavioural supports. It is important for your family to think about how to include your doctor. Consider sharing summaries of your meetings or holding meetings in the doctor's office on a regular basis.

We used to have meetings when things got really bad: All of a sudden we would hear that my daughter is having problems in her day program and

Navigating the treatment system

she would have to switch, or that there were terrible problems in how she was getting along with her roommate and they are thinking about moving her. Then we would start meeting, problem solving, sharing information and things would improve. Once things got better, we used to stop meeting. Finally we realized that we probably needed to just keep meeting, even if things got better, because the only times they got really bad was when we stopped sharing and communicating regularly with each other. We have been holding regular meetings about once every two months in my daughter's doctor's office now for at least three years. Someone comes from her work, her residence and her family, and it keeps us all on the same page. Plus, we have the doctor right there in case there are any potential medical issues to think about. And this way the doctor stays updated on the whole picture. Also, if there are medical issues or feedback from specialist appointments, the doctor can share it with the whole care team at once.

Medication

7

Outline

- Drug therapy for mental health problems
- Using medications for behaviour management
- Medication management
- Drug interactions
- Ongoing treatment
- When medications are not working
- Stopping medication

Medication

DRUG THERAPY FOR MENTAL HEALTH PROBLEMS

Medications are essential to many treatment programs, but they are not the only treatment. In most cases, medications are more effective if they are combined with some of the therapy interventions discussed in Chapter 6.

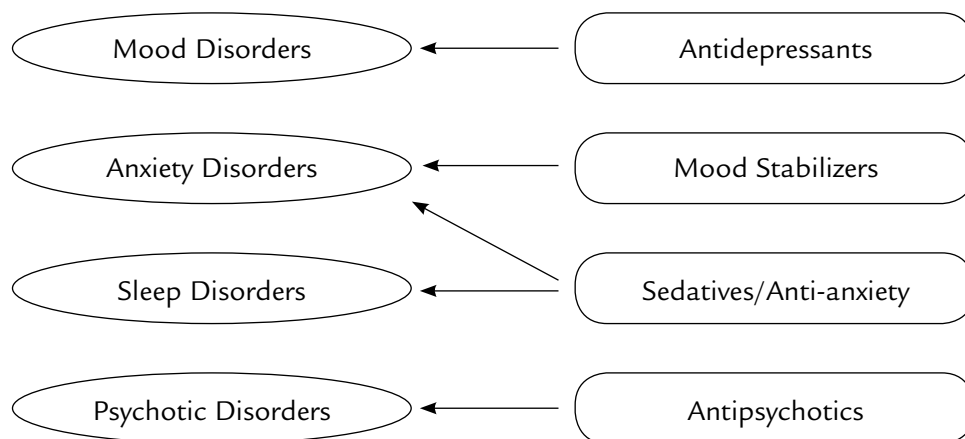
Types of psychiatric medication

Most mental health medications are used to help restore chemical balance in the brain. This can help to reduce the frequency and severity of symptoms. Medications are divided into four main groups based on the problems that they were developed to treat:

- antidepressants
- mood stabilizers
- anti-anxiety medications/sedatives
- antipsychotics.

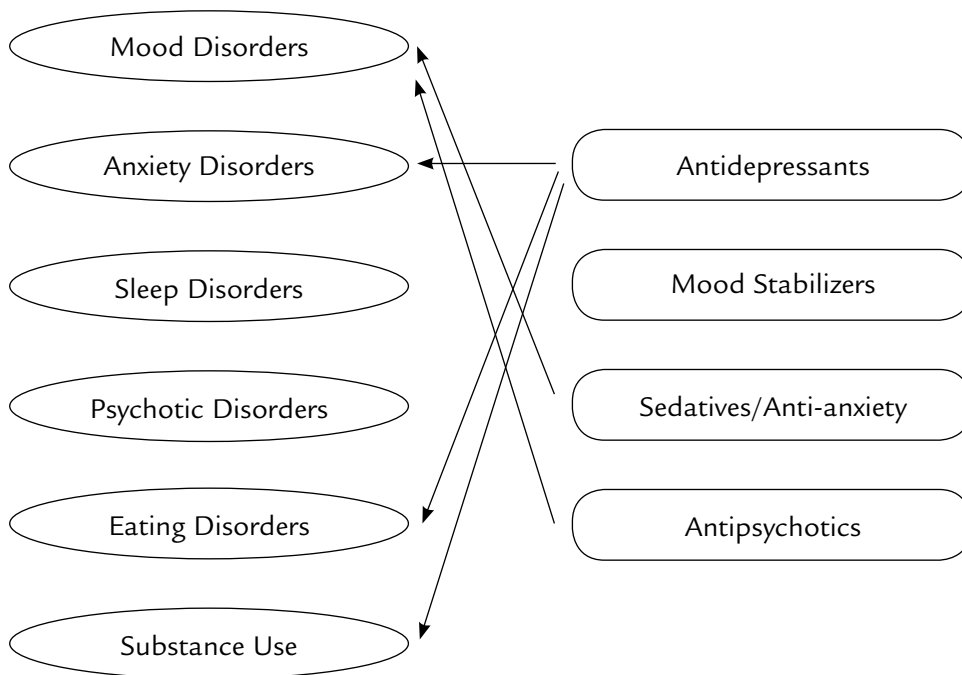
Medications have a generic (or chemical) name and a brand (or trade) name that is specific to the company that makes the medication. For example, the generic antipsychotic clozapine is sold under the brand name Clozaril. The brand name may change depending on the country in which the medication is marketed.

Figure 7-1: Traditional uses for classes of psychiatric medications



Despite the four distinct classes of psychiatric medications listed above, each type of medication can be used to treat various disorders. For example, a person who takes a mood stabilizer to treat bipolar disorder may also take an antidepressant, anti-anxiety or antipsychotic medication to treat symptoms such as depression, sleep problems, anxiety or psychosis.

Figure 7-2: Alternative uses for classes of psychiatric medications



ANTIDEPRESSANTS

Antidepressants work via a number of different mechanisms, but the end result is to increase the level of communication between nerve cells in the brain. While they were originally used to treat depression, antidepressants are also used to treat chronic pain, bulimia, premenstrual dysphoric disorder, chronic fatigue syndrome and anxiety disorders. In fact, antidepressants, especially the class known as selective serotonin reuptake inhibitors (SSRIs) such as Prozac, are used more often to treat anxiety disorders than are traditional anti-anxiety medications such as Valium.

Medication

MOOD STABILIZERS

Mood stabilizers are used to help control mood swings (extreme highs and lows) connected with bipolar disorder, and to prevent further episodes of this condition. Lithium was the first mood stabilizer on the market and is still a useful medication. Other medications used to stabilize mood include anticonvulsants, which were developed to treat epilepsy and other seizure disorders.

Treatment of bipolar disorder initially depends on the person's symptoms. Bipolar disorder may also be treated with antidepressants in combination with mood stabilizers.

ANTI-ANXIETY MEDICATIONS AND SEDATIVES

The main group of medications in this class consists of benzodiazepines, such as diazepam (Valium) and lorazepam (Ativan). While they are legitimate medications for treating anxiety and sleep disorders, they can become addictive if used for more than about four weeks. An anti-anxiety medication that can be used for a longer period of time is buspirone (BuSpar).

ANTIPSYCHOTICS

Antipsychotics reduce the effect of dopamine in the brain. They are traditionally used to treat schizophrenia and other psychotic disorders. The newer, second-generation antipsychotics are now also being tested as mood stabilizers, anti-anxiety medication and even as a treatment for refractory depression (depression that is difficult to treat).

For more information about psychiatric medications, see:

- [Mental Health Medications](#) (published by the National Institute of Mental Health in the United States, available online at www.nimh.nih.gov/health/publications/mental-health-medications/index.shtml)
- Now [Psychtherapeutic Medications 2012](#)—online database available at <http://www.findrxinformation.org/>
- The University of Birmingham has developed resources that explain medications specifically for people with developmental disabilities. Visit www.ld-medication.bham.ac.uk/2erg.pdf.

USING MEDICATIONS FOR BEHAVIOUR MANAGEMENT

It is not always possible to match the symptoms or behaviours of someone with dual diagnosis to a specific psychiatric disorder (see also Chapter 3). Medication may be part of a treatment plan for “challenging behaviour” when the underlying psychiatric disorder is uncertain or unknown. In these situations it is very important to know what the medication is targeting, specifically what the behaviour looks like before intervention and how the behaviour changes with medication (see “Your role in monitoring medications”, p. 108).

Sometimes, as families, we want a “quick fix,” a medication that can help to fix a complex problem. We hope a medication can help because it is so difficult to manage the current situation. It is important to understand that there is no medication that can offer a quick fix that does not have its own problems. Medications, particularly antipsychotics, have historically been used to sedate people exhibiting challenging behaviour. However, there is limited research to suggest that medication for this purpose works in the long term. Sometimes, the side-effects of these medications can lead to further distress and agitation.

These two examples illustrate how medication side-effects can be a part of the problem and why it is important to monitor medication:

Example 1

A parent's perspective

Our son has autism and he is non-verbal. Last year, things got much worse for him. He was getting more agitated and aggressive, and our doctor prescribed medication with the aim of helping to calm him down. Instead, he became more aggressive, and so more medications were added. Eventually he was admitted to an inpatient hospital setting because his aggression could not be managed in the community. The multidisciplinary team at the hospital did a comprehensive physical exam, and discovered that he was constipated—which was one of the major side-effects of the medications he was taking. After taking him off the medications under the supervision of a psychiatrist, and helping him with his constipation through diet and regular monitoring, his aggression subsided and he was able to come back home.

Medication

Example 2

A parent's story

Our doctor decided, since my daughter had all these problems with impulsivity and keeping her attention on any one task, he would do a medication trial of Ritalin. I have always objected to medications because I worried that my daughter would be dopey or “drugged up.” The way our doctor did it, he had her taking the medication for two weeks, off for two weeks and then again two weeks on, two weeks off. But we didn’t know which weeks were on or off. The group home, her day program and our family kept track of what she was like for each of these two week periods and then we all got together after the eight weeks to talk about it. First her group home spoke about how difficult the first two weeks were, lots of agitation, not able to be with others, spending time in her room, yelling and skin picking. The next two weeks she was better and really interacting more with her roommates, doing some things she had never been able to do before! Same pattern over the next four weeks. The day program spoke next and they couldn’t agree more with the group home. In the first two weeks things were difficult. She was having outbursts, not able to stay still for long and complete tasks. But in the next two weeks, she was reading to other clients, working in the kitchen and taking on some new responsibilities. We almost didn’t see the need to open the envelope because it was so obvious when she was on the medication. Everyone was quite pleased and glad that we took this systematic approach to watching her on and off medication. Then the doctor opened the envelope, and to our surprise we learned that the first two weeks were on the medication. The behaviours everyone saw which they assumed were just her were actually her on a medication that didn’t agree with her. Even the skin picking wasn’t noticed as a side-effect. When she was off medication but everyone was feeling like something was working, opportunities opened up for her. And with more opportunities, she just did better. It was a huge lesson for all of us about the importance of really monitoring her behaviour, and sharing information with each other. I think it also taught us how quick we are to attribute successes to medications and how blinded we can be to side-effects if we aren’t looking for them.

MEDICATION MANAGEMENT

Pharmacotherapy for people with developmental disabilities is particularly complex. Medications should be part of a broader approach and require careful monitoring, particularly when the person cannot articulate their experience with the medication and report side-effects. *The Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines* recommend that medications be reviewed every three months, and that comprehensive reviews of complex medication regimens be reviewed annually (Sullivan et al., 2011).

While full remission can happen on medication for some people, the amount of symptom relief varies from person to person. There is still a great deal of trial and error involved in finding the best medication for each person. You and your family member should be involved in the decision-making process and be given information about the benefits and risks, including side-effects, of medications. It is important to be aware that medications can interact with one another; asking the doctor about this can be a way of troubleshooting.

Identifying and minimizing side-effects

It is very difficult for people with developmental disabilities to self-report side-effects. Family members should work with the treatment team to identify potential side-effects of each medication and figure out ways to monitor them objectively, focusing on observable behaviour. Side-effects may increase or decrease over time and can range from mild discomfort to problems that are severe enough to make it impossible to cope with day-to-day life. People often stop taking medication because of unpleasant side-effects without reporting them to anyone. It is dangerous to stop or change medication without consulting the treatment team.

The treatment team can suggest ways to minimize side-effects. Strategies include:

- taking the medication in smaller doses spread over the day
- taking medication with appropriate food
- taking an additional medication to treat specific side-effects
- changing the medication.

It is sometimes surprising how much of a difference even a very small dosage adjustment can make in how someone responds to treatment or is affected by side-effects. While a higher dose may be needed to control an acute episode, a person can generally be kept on a lower dose. The dose may need to be changed over time.

There are some practical, non-pharmacological strategies that your family member can use to deal with side-effects. Some of these are listed in Table 7-1.

Medication

Table 7-1: Managing common side-effects

ANTICHOLINERGIC EFFECTS	
Side-Effect	Management Strategies
Dry mouth	<ul style="list-style-type: none"> • chewing sugarless gum or sucking on sugarless or sour candy (both dry mouth and excess sugar can increase the risk of tooth decay) • ensuring good mouth hygiene, including frequent brushing, flossing and use of mouthwashes • having regular dental checkups • using oral lubricants (e.g., MoiStir)
Dry eyes and/or blurred vision	<ul style="list-style-type: none"> • getting a prescription for eye drops
Constipation*	<ul style="list-style-type: none"> • increasing fluid intake (e.g., water, juice and other non-caf-feinated, non-alcoholic beverages) • increasing regular physical activity and exercise • increasing dietary fibre (e.g., bran, raw fruits and vegetables) • trying a bulk laxative (e.g., Metamucil, Prodiem) or stool softener (e.g., Surfak, Colace) • avoiding regular use of stronger or stimulant laxatives (e.g., sennosides [Senokot], bisacodyl [Dulcolax])
Urinary retention	<ul style="list-style-type: none"> • if mild, patience and running water while attempting to urinate • if more severe, a prescription medication to help counteract this effect

*It is important to carefully monitor stool in anyone who cannot reliably report on frequency and consistency of stool themselves. This may seem like an invasion of privacy, so it should be done in a way that empowers the person to self-report. There are helpful charts that people with disabilities can be taught to use to track how they are doing. Constipation can not only be uncomfortable, it can also cause significant pain and lead to more serious medical complications, including ruptured bowel and even death.

CENTRAL NERVOUS SYSTEM EFFECTS	
Side-Effect	Management Strategies
Drowsiness	<ul style="list-style-type: none"> • taking most of the dose, or the full dose if possible, at bedtime
Lack of muscle co-ordination or muscle weakness (ataxia)	<ul style="list-style-type: none"> • checking with a doctor since it may be due to too high a dose
Headache	<ul style="list-style-type: none"> • trying over-the-counter headache remedies such as acetaminophen (Tylenol), acetylsalicylic acid (Asprin) or ibuprofen (Advil)—but first asking a doctor or pharmacist to check for possible drug interactions • getting a prescription for a different medication if, with time, headaches don't go away

INCREASED ENERGY (ACTIVATION EFFECT)	
Side-Effect	Management Strategies
Extrapyramidal effects (tremor, restlessness, muscle stiffness and spasms, difficulty walking)	<ul style="list-style-type: none"> • adjusting the dose (done by doctor) • getting a prescription for anti-Parkinsonian drugs (e.g., benzotropine [Cogentin]—but this medication must be monitored, as excessive doses may cause other side-effects such as disorientation, confusion and delirium) • taking propranolol, a prescription medication used to treat tremor or restlessness • taking a benzodiazepine (e.g., lorazepam [Ativan]) to treat restlessness

Medication

GASTROINTESTINAL EFFECTS	
Side-Effect	Management Strategies
Nausea	<ul style="list-style-type: none"> • taking medications with meals, having small snacks or drinking milk • not using antacids within two hours of taking the medication, as they may interfere with drug absorption
Diarrhea	<ul style="list-style-type: none"> • trying loperamide (Imodium) or attapulgite (Kaopectate) after checking with a doctor or pharmacist for any drug interactions • taking smaller doses throughout the day or—if the diarrhea is the result of taking lithium—using a slow-release preparation (sudden diarrhea may indicate lithium toxicity)

CARDIOVASCULAR EFFECTS	
Side-Effect	Management Strategies
Dizziness, fainting	<ul style="list-style-type: none"> • getting up slowly from a lying or sitting position and dangling feet • wearing support hose and doing calf exercises to reduce blood pooling in the calves • taking the drug in smaller, divided doses throughout the day
Rapid heartbeat	<ul style="list-style-type: none"> • reporting this side-effect to a doctor—however, this is usually not a serious problem
High blood pressure	<ul style="list-style-type: none"> • speaking to a doctor about reducing the dose, changing medications or adding a high blood pressure medication

OTHER	
Side-Effect	Management Strategies
Weight effects	<ul style="list-style-type: none"> • reducing carbohydrate and sugar intake and consulting a dietician, if possible • increasing physical activity and exercise
Sexual side-effects*	<ul style="list-style-type: none"> • reporting these side-effects to a doctor, as all treatments for this side-effect involve prescription medications • trying a different drug, if these side-effects don't go away over time
Difficulty regulating extreme changes in temperature (altered thermo-regulation)**	<ul style="list-style-type: none"> • spending only a short time in saunas or out in the sun on hot humid days due to increased risk of sunstroke • drinking plenty of fluids and staying in the shade as much as possible • wearing loose-fitting clothing and a wide-brimmed hat • avoiding overexposure on freezing days due to increased risk of hypothermia
Photosensitivity	<ul style="list-style-type: none"> • avoiding prolonged sun exposure • wearing loose-fitting clothing and a wide-brimmed hat • always using sunscreen with an SPF of 15 or higher
Excessive sweating	<ul style="list-style-type: none"> • using talcum powder and a stronger antiperspirant (e.g., Drysol) for greater comfort • speaking to a doctor about reducing the dose • speaking to a doctor about adding another medication if a severe case

*The impact of these side-effects is not limited to people engaging in sexual relations with others. For example, some men can experience serious distress because a medication they take causes difficulties reaching a climax while masturbating.

**It is important to watch a person with a disability who cannot report their own temperature. It becomes the caregiver's role to keep them comfortable, hydrated and dressed appropriately.

Medication

Questions for the doctor or pharmacist about medication

- What is the name of the medication, and what is it supposed to do?
- How and when is it taken, and when should a person stop taking it?
- What food, drinks or other medications should be avoided while taking the prescribed medication?
- Should the medication be taken with food or on an empty stomach?
- Is it safe to drink alcohol while on this medication?
- What are the side-effects, and what should be done if they occur?
- Where is information about this medication available?

(National Institute of Mental Health, 2002)

Your role in monitoring medications

Make sure you and your family member know the name and dose of each drug and why it has been prescribed. The easiest way to do this is to get a printout from your local pharmacy that lists current and past prescriptions. This information should be stored in an accessible place and always available in case there is an emergency or a visit to a physician who does not have the most updated medication list on file.

Remember that physicians can use medications to treat all types of problems and that a medication for a physical problem might interact with a medication for a psychiatric issue. Everyone who prescribes medications needs to know the complete list.

You can also help with monitoring by:

- ranking symptoms of the illnesses on a scale of one to 10 and reporting any improvement
- noting side-effects and discussing them with the treatment team
- checking with a doctor and/or pharmacist for drug interactions before your family member takes any new medication (prescription or over-the-counter).

Activity 7-1: Tracking side-effects

Try working with your family member to compile a record of medications and side-effects. This can be useful when you meet with the treatment team.

A: Side-effects		
Date	Side-effect noted	
B: Medications		
Date	Medication	Dose

DRUG INTERACTIONS

A drug interaction occurs when one drug alters the action or effects of another drug also present in the body. Some interactions are trivial, while others can be dangerous and even life-threatening.

Drugs taken together:

- can act independently of one another. For example, alcohol does not seem to interfere with the action of vitamins or oral contraceptives, or vice versa.
- can increase one another's effects. This could happen because the drugs affect the brain in the same way or because one drug increases the concentration of the other in the body. For instance, alcohol and antihistamines are both central nervous system depressants. Therefore, the combination can increase both the desired effects of the drugs (e.g., disinhibition or decreasing of self-control) as well as the side-effects (e.g., drowsiness)
- can decrease one another's intended effects (an antagonistic effect). This could occur when one drug "blocks" or prevents another drug from producing its effect. It could also happen when two drugs have opposite effects on the brain (e.g., alcohol-induced drowsiness versus caffeine-induced alertness).

Consequences of drug interactions

An important factor in choosing a medication for someone with both medical and psychiatric issues is to pay attention to potential toxic interactions.

TOBACCO AND ANTIPSYCHOTICS

Smoking decreases the blood concentration level of certain antipsychotics by 20 to 100 per cent, so smokers require higher doses. If a person reduces or quits smoking while taking an antipsychotic, the blood concentration levels of the drug will increase, leading to increased side-effects and possibly toxicity. Therefore, dose decreases are usually required, but must be monitored closely.

TOBACCO AND BENZODIAZEPINES

Some of the substances in tobacco can induce the liver enzymes that metabolize diazepam and chlordiazepoxide. This causes them to clear from the body more quickly, leading to a need for higher doses.

CAFFEINE AND LITHIUM

Caffeine (found not only in coffee, but also in chocolate and soda) acts as a diuretic, which can worsen incontinence. This affects water balance and can therefore affect lithium levels. Caffeine can also increase excretion of lithium from the kidneys and lead to lithium tremor. People who take lithium may still have some caffeine in their diet, but it is important that they do not drastically change their intake from day to day.

SEIZURE THRESHOLD

Many people with developmental disabilities can be at risk of having a seizure disorder, and it is important to monitor how difference medications can increase the risk of seizures.

ONGOING TREATMENT

Clients, as well as their families, are often very concerned about how long they will be taking medications. In some situations, the treatment will be short-term, as in the case of a sleeping pill for temporary insomnia. For a first episode of depression, medication is recommended for at least one year. For bipolar disorder and schizophrenia, the period of treatment is usually indefinite to prevent symptoms from returning.

Some mental health problems are lifelong conditions, so treatment with medications may be indefinite. Once an acute episode has been successfully treated, you, your family member and the treatment team need to watch for signs of possible relapse.

Some mental health problems are temporary, so it is important to examine whether the medication should be continued.

WHEN MEDICATIONS ARE NOT WORKING

It is important to give feedback to the treatment team about how well medication is working. Any time a new medication is prescribed, it is a good idea to schedule a follow-up meeting so the treatment team can consider whether the medication change is effective.

Many people with developmental disabilities are prescribed multiple medications without anyone asking if they are working. If they are not working, the side-effects can contribute to difficulties.

Medication

My brother had been numerous medications for almost 10 years He became very quiet, slowed down and sluggish. He also gained a lot of weight and didn't have the energy he used to have. Over those 10 years we began to feel that this was "just who he was" and forgot about his old energetic self that was always on the go. However, he began to get upset with this sluggish self and slowly became more aggressive and began lashing out, always telling us "he didn't feel well" or "wasn't happy." It was a long and painful process, but we eventually realized that he was likely over-medicated. Once this issue was cleared up, we saw a re-emergence of his old self. With the right balance of medication, he could be happy and energetic but also have his psychiatric issues under control.

Start low, go slow

A systematic approach is required when trying new medication. "Start low, go slow" is the mantra of a strong team that is trying to find the best medication combination for someone with complex difficulties. It is best to have a team that includes a community nurse and/or a behaviour therapist who can assist with medication monitoring. If your family member seems stable on the medication or is experiencing side-effects, the doctor may take a slow approach of tapering (reducing) the medication. If this starts to make things worse, the medication can be adjusted back. It might not be the right time to make this kind of adjustment. Some people may need to stay on medications long term.

Your input is important when making medication modifications. First of all, you can report on how the adjustment is going: Are symptoms worse? Are side-effects better? Also, you may be the only person who can help the doctor decide if this is a good time to make changes to a medication regimen. If there are significant changes in your family member's routine or living situation, it might not be the best time to monitor medication changes because it is impossible to know how much of the change is due to the life situation and how much can be attributed to the medication. For example, changing medications just before going on a family vacation, finishing school or having a family member move out of the house might not be a good idea.

STOPPING MEDICATION

Both people with disabilities and their families are often ambivalent about long-term medication use. They may want to stop their medication because they:

- experience unpleasant side-effects
- feel well and no longer see the need to take medications
- get messages from others that medications are harmful and not necessary
- have concerns about medication interactions.

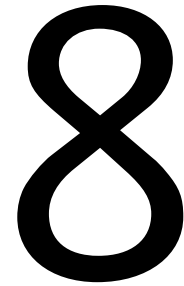
Stopping medication should always be supervised by a physician. The body needs to adjust, so stopping—or changing—medication should be done slowly and carefully.

Families should encourage their family member to talk about problems with their medication so they can explore what could happen if they suddenly decide to stop taking a medication. If your family member chooses not to take their medication, here is how you can address the decision with them:

- Acknowledge that they have a right to choose not to use any medication.
- Stress that they owe it to themselves to make sure their decision is well thought out. It is an important decision about their personal health and they need to discuss it with their doctor.
- Ask about their reason for choosing not to take the medication.
- Don't accept "I just don't like pills." Tell them that you are sure they wouldn't make such an important decision without having a reason.
- Offer as examples reasons others might choose not to take medication. For example, they:
 - don't believe they ever needed it (i.e., they were never mentally ill)
 - don't believe they need it anymore (i.e., they are cured)
 - don't like the side-effects
 - fear the medication will harm them
 - struggle with objections from or ridicule of friends and family members
 - feel that taking medication means they're not personally in control.

Medication is often an important part of a treatment plan for dual diagnosis, but finding the most effective medication, or combination of medications, can be a long, frustrating process. You can help by learning about the benefits and risks of the medications that your family member is taking, and by talking with them and the treatment team about how the medication is working, and the nature and severity of side-effects. Make sure that the medication and dosage are reviewed regularly. If you are not satisfied, you and your family member can ask for a second opinion.

Crisis and emergency



Outline

- Understanding crises and emergencies
- Whose crisis is it?
- Being prepared
- During a crisis
- When a crisis becomes an emergency

UNDERSTANDING CRISES AND EMERGENCIES

Even the best planning can't always prevent a crisis. A crisis may occur with little or no warning.

A *crisis* is any serious deterioration of a person's ability to cope with everyday life. It can be a turning point—for better or worse. It does not necessarily involve a danger of serious physical harm. A crisis develops when people feel they cannot control their feelings and behaviour and have trouble coping with the demands of day-to-day life. Although people in crisis are not necessarily a danger to themselves or anyone else, in many crisis situations, outside help is needed. This can come from the person's doctor or therapist or from a mobile crisis service or crisis line.

An *emergency* is a situation that involves an immediate danger that the person will harm either himself or herself or someone else (Chan & Noone, 2000). Examples of emergencies include:

- threats of suicide
- threats of physical violence
- extreme impaired judgment caused by problems such as psychosis or intoxication.

WHOSE CRISIS IS IT?

Sometimes issues related to dual diagnosis happen suddenly. The person's symptoms, problems and needs create a crisis that galvanizes the entire family into action. At other times, issues can unfold slowly and may build until someone in the family decides that it's time to take action. Sometimes a sudden change in daily routine triggers a crisis that escalates into an emergency. Sometimes there is nothing that family members can do to prevent a crisis. Sometimes family members can prevent—or trigger—a crisis.

An example of sudden crisis: *Bill has a developmental disability. He likes his routine to be the same everyday, including who helps him with his activities. One day, Bill's caregiver unexpectedly becomes sick and cannot help him. A new person who does not know Bill well and who Bill does not know comes to help him. This new caregiver does not know what Bill likes or does not like. Bill becomes frightened and uncomfortable about this unexpected change in his routine. He is unable to express his needs and becomes agitated and very aggressive to the point where his safety and that of others in the community is at risk. The new caregiver feels he has no choice but to call an emergency service to help because the situation can no longer be handled without added supports.*

An example of a slowly growing crisis: *Many family caregivers speak about working very hard all the time to avoid a crisis. They describe it as “walking on eggshells, trying not to break one.” They manage the situation as best they can, making changes in the environment to support the needs of their family member with dual diagnosis. The adjustments help temporarily, but do not seem to stop the aggression from coming back. Eventually, there are no more changes that can happen in the environment, and the mild aggression becomes severe to the point that it cannot be managed in the community.*

Here is an example: *John is an adult with a developmental disability and has always lived with his mother, who knows him quite well. Since adolescence, John has had intense moods that sway between intense sadness and uncontrollable happiness or agitation. His mother makes sure that whenever John starts to show an intense mood, she is there to comfort him, remind him of strategies that have helped in the past, change the environment to help him or give him his medication. She is not sure if the medication really helps or not, but she tries it anyway. Lately, the medication has been helping less and less, and no matter what John’s mother tries, his moods continue to become very intense. She keeps trying what has worked before and cannot think of anything else to try. She says, “I’ve tried all the tricks, but nothing seems to work anymore!” She contacts John’s case manager because she is scared about his depression and anger. The case manager thinks that John’s behaviours and mood have escalated to the point where emergency care is needed.*

As these examples illustrate, the perception of a situation may vary among family members and other care providers. One person may think that the situation has become a crisis that requires immediate action, whereas someone else may not. Sometimes professional care providers feel that something has suddenly gone seriously wrong and needs immediate attention, while family members or the person with the disability aren’t as concerned. In other situations, family members are convinced that action needs to be taken, but the person with the dual diagnosis or professional care providers may not agree or may be afraid of what taking action will mean for them.

So you need to ask yourself, Whose crisis is it? The answer will help you to understand who is really asking for help—your family member, the family, other caregivers or all of these people.

BEING PREPARED

Being prepared can help to prevent a situation from developing into a crisis and can also ease the pain and anxiety for the person and the family if a crisis does occur. Have

Crisis and emergency

a safety team in place before a crisis happens. This safety team can involve any services and individual workers that you have identified as potentially helpful. Have their phone numbers on hand, and make sure that they have agreed to be part of the team. There are various ways to prepare for a crisis, such as developing a crisis plan or preparing crisis cards.

Creating a crisis plan

The Primary Care Initiative website provides an [example of a completed crisis prevention and management plan](#) that can be helpful. The following guidelines will help you to create a crisis action plan that is tailored to the needs of your family member:

- Make sure that your family member is actively involved and participates in the discussion as much as possible, and that their preferences are heard and respected. For example, if your family member sometimes needs to be restrained when very upset in hospital and prefers physical restraints over forced medication, that information should be recorded.
- Involve as many members of your family as deemed appropriate and develop an approach that everyone can agree upon.
- Develop very specific steps for carrying out your plan. Decide what role each member will have in implementing it. For example, decide who is the best person to accompany your family member to the hospital if it becomes necessary, who should stay on at the hospital and who should make phone calls from home.
- Decide who will speak to the treatment team—or in extreme situations to the police—if your ill family member is unable to do so.
- Make sure to get your family member's permission to relate particular information to hospital staff or to the police.
- Get input on how to create a crisis plan from your treatment team. Behaviour therapists in particular may have experience with preparing a crisis plan that everyone can review and sign.
- Especially if your family member has visited a hospital in the past, be sure to involve it in your crisis planning. Hospital staff may have some good ideas about how to make the emergency visit less stressful. If they see a crisis plan that had their input, they will be more likely to follow it and give you the support you need. If crisis plans are created without hospital input, the expectations placed on staff may not be realistic. A good person to approach to help with this planning might be a crisis nurse or social worker who was involved in a previous visit.
- Consider how the crisis plan can be shared with hospital staff if your family member is likely to go to hospital without informing or involving family. Crisis cards might be one way of doing this.

Crisis cards

People with dual diagnosis and their family members have found it very helpful to write important information on a card or a piece of paper folded small enough so that it can be carried with them wherever they go. The paper may be placed in a visible part of the person's wallet.

A crisis card usually contains information that is important for others (e.g., friends, health care workers, police, strangers) to have in the event that your family member experiences a mental health crisis while away from home. The card contains information about your family member, such as:

- important phone numbers—who to call in the event of a crisis or an emergency, including who to call first and who to call as a back-up
- their mental health doctor (e.g., psychiatrist), therapist or worker
- their family doctor
- the hospital or treatment centre at which they currently receive or have previously received inpatient or outpatient care
- a list of their current medications, the proper dosage for each and when they are to be taken (you may also wish to include the name and phone number of the pharmacy where the prescriptions are usually filled)
- a list of medications to which they are allergic
- any medications used in the past that did not work, or that your family member would not take due to side-effects (you may list such medications in one column and list side-effects in a second column)
- tips for effectively talking to and working with them when they are in crisis—neutral topics of interest to them for either engagement or distraction; comforting foods; self-calming measures, such as music or video games.

[MyHealthPassport](#), developed by the Good 2 Go transition program at the Hospital for Sick Children, is an online interactive tool that organizes information into a wallet-sized card that can be downloaded and printed.

DURING A CRISIS

When a person with dual diagnosis experiences a crisis, the family should:

- try to be calm and supportive
- offer to call the contacts on the identified safety team: the doctor, day program worker, case manager or whoever else has been identified in the plan. If possible, ask your family member if they wish to talk with any of these people on the phone.

Following through on these suggestions might help to prevent a crisis from becoming an emergency. However, it is important to be aware that sometimes an emergency cannot be avoided. It is helpful to know what you can do in the event of an emergency.

WHEN A CRISIS BECOMES AN EMERGENCY

If your family member threatens to harm himself or herself or you, or to seriously damage property, you must do whatever is necessary to protect yourself and others (including your family member) from harm. You may need to leave and call for help. This is advisable only under extreme circumstances, and only for very short periods of time. If possible, remove objects with which your family member could harm himself or herself.

Don't:

- shout
- criticize
- stare
- argue with others about what to do.

Suicide

One of the most terrifying aspects of a serious psychiatric disorder is hearing your family member talk about suicide. Any talk—even joking—about suicide must be taken seriously.

Most people do not want to end their lives. Suicidal thinking or attempts typically occur during a serious episode of mental illness when the person feels helpless and hopeless and is in a state of despair. Although the feelings are often temporary, at the time, the person may not believe that the feelings will pass. You can help by acknowledging your family member's feelings while offering to help them find other solutions. However, it is also important to recognize your own limitations. Family members must realize that they do not have absolute control to change things and cannot be responsible for all of their family member's actions.

WARNING SIGNS OF SUICIDE

There are several warning signs that a person is considering suicide. They may:

- discuss suicide and what it would be like to have things end
- be concerned with providing for children, other family members or pets
- give away possessions
- express feelings of worthlessness, such as, "I'm no good to anybody"
- feel hopeless about the future, reflected in comments such as, "What's the use?"
- talk about voices that tell them to do something dangerous.

What to do if you find someone after a suicide attempt

- Phone 911 immediately.
- If you know first aid, administer it immediately.
- Phone someone to accompany you to the hospital or to stay with you at home.

Do not try to handle the emergency alone; contact a support group to help you with your immediate reactions and long-term feelings.

Getting treatment in an emergency

GOING TO THE HOSPITAL

It is best if you can get your family member to go to the hospital voluntarily. If they won't listen to you, ask someone else whom your family member trusts to convince them to go to the hospital. This should be part of your emergency plan. Try to offer your family member a choice. This reduces their fear that they are being coerced.

CALLING THE POLICE

If your family member appears likely to endanger himself or herself or someone else and refuses to see a doctor, you can get a judge or justice of the peace (depending on the province or territory in which you live) to issue a document that authorizes the police to take your family member to a hospital for an assessment. But if you're in an emergency situation—if the danger is immediate—call 911.

It's understandable that families may be reluctant to call the police, but extreme circumstances may leave you no other choice. Sometimes, telling your family member that you are calling the police will calm them down. For others, this can make them very agitated.

When you call 911, tell the emergency operator that your family member needs emergency medical assistance and give the operator their diagnosis. Tell the operator that you need help getting your family member to the hospital and repeat their diagnosis.

In some communities, the police receive training in crisis intervention. It's helpful to find out what kind of training, if any, the police in your community have so you'll know in advance how much advocating you might have to do when and if you need to call the police. If you find yourself in a situation where you need to call the police, write down the officers' names, badge numbers and response time in case you later need to report any concerns about how the problem was handled. While the police are present, you may have time to call the doctor or any other emergency contact.

Crisis and emergency

Involvement with the forensic mental health system

Even when your family member has been destructive or physically abusive, you may be reluctant to involve the police because you want to ensure that the problems are treated as mental health rather than criminal issues. Families sometimes fear that their family member will be put in jail, where they may be victimized and treated inappropriately.

But failing to take seriously the risk of violence and physical harm can have its own consequences. You should take care to recognize the signs of escalating threats and violence, the presence of extra stress and triggers that could set off your family member and know when things are beyond your control. Don't be afraid to call a crisis team or the police to your home. In many cases, that is the safest, kindest thing you can do for an ill family member.

If you are not in an emergency situation but you would like your family member to get an assessment, they must agree and sign themselves in to a hospital voluntarily. Getting a health care facility to hospitalize a person who is opposed to treatment is only possible if the person meets the criteria for involuntary admission (see p. 125). Even then, the person is often discharged before they have been fully treated if they choose not to continue with care.

Ironically, if a person with serious mental health conditions comes before a judge because he or she has been charged with doing something illegal, it may be more likely that they will be remanded for a full assessment and possibly treatment. Forensic psychiatry is a branch of mental health that works with people who have become involved with the law. For some people who have mental health problems and have become involved with the law, being directed to a forensic facility allows them to receive the care that they have not been able to receive in the community system.

The forensic mental health system can be confusing for families. If you live in Ontario, *The Forensic Mental Health System in Ontario: An Information Guide* (available at www.camh.net/Publications/CAMH_Publications/forensic_menthealth_infoguide.html) will help you to find your way through the system. There are special case management services for people with dual diagnosis and forensic involvement that can be accessed by contacting the Community Networks of Specialized Care (www.community-networks.ca). If your family member is involved in the forensic system, you can ask your CNSC health facilitator about the special forensic case manager in your area.

YOU HAVE CALLED 911—NOW WHAT SHOULD YOU DO?

Icovino and Esralew (2009) provide some helpful suggestions for what you can do after you have called 911:

1. If you don't feel safe doing so, do not attempt to transport your family member to the nearest emergency room by yourself!
2. While waiting for the police to arrive, try to make your surroundings as safe as possible by removing dangerous objects.

3. Tell the 911 dispatcher that the person in crisis has a developmental disability. This will alert the police, who are usually the first responders, to avoid unnecessary force. This includes not having weapons drawn upon arrival if they know the person is aggressive. If there are enough family members around, have someone meet the emergency personnel before they enter the home and remind them that the person in crisis has a developmental disability.
4. Other people who do not need to be present to support the person in crisis should leave or be removed to a safe area.
5. If the person in crisis needs to visit the hospital, emergency staff will arrange transportation. You can follow the ambulance or police to the hospital in your own vehicle. You can also ask about riding with your family member in the ambulance.
6. If you have an emergency plan, take it with you when you travel to meet your family member at the hospital. The advocacy organization Autism Speaks has developed some excellent tools for police and other first responders to help them work with your family member (see *Creating a Crisis Plan* p. 118)

The video [Using Emergency Services](#) offers practical advice on calling 911, working with the police and things to remember when going to the hospital.

WORKING WITH HOSPITAL EMERGENCY STAFF

If possible, go to the emergency department with your family member. The staff should interview you because you have information that they need to decide how to treat your family member. If emergency room staff doesn't ask to talk to you, you should insist that you get a chance to talk to them.

Try to provide an organized account of the events leading up to the hospital visit. If you are worried about your safety if your family member is released, let the staff know.

Many emergency room staff don't have much experience working with people with developmental disabilities. You can help them to understand your family member's needs by coming prepared. It may be a good idea to bring:

- comforters (e.g., security blanket, stuffed animal, favourite book, photos)
- favourite food/drink and snacks (the wait can be long and food may be limited)
- communication strategies that help your family member to confidently talk about themselves
- ways to illustrate what your family member is like when they are not in crisis (e.g., photos or video/digital materials)
- entertainment/activities to stay occupied while waiting (game, book, portable DVD player).

Also be sure to bring all medications for the next 12 hours because the emergency department will not dispense regular medications.

Crisis and emergency

WHAT TO EXPECT IN THE EMERGENCY DEPARTMENT

You may be asked to sign a consent form for emergency room treatment for your family member and to complete a general information form.

You will be required to provide your family member's Ontario Health Insurance Plan (OHIP) card, as well as their address and birthdate.

You will be seen by a nurse who will ask you and your family member some general questions about why you came to the emergency department. This nurse decides how urgent your situation is and directs you where to go next to wait and see a doctor.

You will see a doctor (an emergency physician) who may ask some of the same questions. As part of this assessment, your family member may have a physical examination to rule out any medical causes.

The doctor may decide that your family member is ok to go, may make some care suggestions or may decide that your family member should be seen by a psychiatrist or mental health team. If the doctor thinks that your family member should be seen by a psychiatrist, you will wait again.

The psychiatrist or mental health worker will ask more detailed questions about the current situation, history of problems, past treatments, visits and medications. Some questions will be for you and some will be for your family member. If you think the psychiatrist or mental health worker should talk more to your family member, say so. If you want to tell the psychiatrist or mental health worker something in private, let them know.

The video [What to Expect When You Go to the ER](#) is an overview of an ER visit, and can be found in the references at the end of this publication.

WHY DOES YOUR FAMILY MEMBER NEED A MEDICAL EVALUATION?

The emergency physician may decide that your family member needs a medical evaluation. These evaluations are particularly important for people with developmental disabilities because of the difficulties they have communicating pain and medical issues. The medical screening allows the team to rule out any infections or major medical problems that might be affecting your family member's behaviour. Keep in mind that even with a medical screening, some medical issues including dental problems may be missed.

WHY MUST YOU WAIT IN THE EMERGENCY DEPARTMENT?

One of the most difficult challenges for anyone visiting an emergency department is waiting. It is probably more difficult for those with developmental disabilities. You might start to think that the wait is because hospital staff doesn't understand developmental disabilities. But remember that everyone waits in the emergency department. It is also important to remember that the amount of time you wait can vary, depending on what else is going on in the emergency department at that time. Be prepared to wait between two to 12 hours from start to finish.

If possible, while you are waiting in the emergency department, let your family member's doctor know about the crisis. It is important to follow up with the doctors after the visit and bring them documentation from the emergency department. Before you leave the hospital, ask the emergency physician whether documentation will be sent directly to the family doctor.

INVOLUNTARY ADMISSIONS

Your family member may not want to get treatment when in crisis. In Canada, a person can't be forced to get treatment for a psychiatric disorder unless they are a threat to themselves or others. While this approach acknowledges the rights of the person, it has created complex problems for families. If a person who doesn't want to be admitted to hospital is admitted, they are considered an involuntary patient. The specific criteria used to decide whether a person can be admitted to hospital without their consent vary, depending on the province or territory. However, there are some basic criteria:

- The person is believed to be a danger to himself or herself (e.g., is suicidal or self-harming).
- The person is believed to be a danger to others (e.g., is violent).
- The person is unable to care for himself or herself and is at immediate risk as a result (e.g., because he or she is not eating or drinking).

If the person meets the criteria for involuntary admission, a physician can issue a document that authorizes a short stay in the hospital for an emergency assessment (usually one to three days). In some provinces and territories, another document must be issued for longer-term treatment. The situation gets more complicated if your family member does not have the capacity to consent to treatment. It is important to discuss that situation with the physician at the time of admission.

Crisis and emergency

AFTER THE EMERGENCY IS OVER

It is very important to debrief about what happened. If there is a crisis plan, talk about how it well worked and if any changes need to be made.

It is best to include the full treatment team in the debriefing session, along with anyone who was involved in the emergency event. It is particularly important to include the primary care physician in the discussion or to inform them about the outcome of the discussion. If there is not yet a crisis plan in place, now is the time to develop on (see the Crisis Plan section on p. 118)

REFERENCES

Chan, A. & Noone, J.A. (2000). *Emergency Mental Health Educational Manual*. Vancouver: Mental Health Evaluation and Community Consultation Unit, University of British Columbia.

Icovino, D. & Esralew, L. (2009). *Family Crisis Handbook: How to Cope When an Adult Loved One with a Developmental Disability Experiences Mental Health or Behavioural Issues*. Hamilton, NJ: New Jersey Department of Human Services Dual Diagnosis Task Force.

Family stories

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Family stories

Supporting a family member who has a dual diagnosis has its challenges. There are times when families face problems that seem impossible to solve. Yet the journey also has its share of triumphs and blessings.

We end this guide with stories from two families that have experienced both struggles and successes in their journey. The families share lessons they learned as they worked to build a system of support for their children.

Life is a journey, not a destination

When you are blessed to have a child, your immediate expectations are of a life fulfilled as you help shape your child to face the outside world. You have pride of parenthood and wonderful dreams for your child. You envision a positive life, supported by the best opportunities, and an expectation that your child will follow the timeworn path to adulthood with some scrapes and bruises along the way, but mostly successes. If not a perfect journey, you hope for a fruitful, contented journey.

Our daughter was born with a condition that slowed her development. She didn't walk or talk until the age of two. Up to that time, all movement was aided and communication was as simple as pointing and screaming. It became apparent very early on that we were dealing with considerable issues, but it was unclear what those issues were and, more significantly, what the future held.

For the next number of years, our daughter underwent physical therapy to improve her motor skills. She seemed to manage day to day quite well. We were aware she wasn't like most kids, but she seemed happy. She built some good friendships and was coping. Unfortunately, her coping skills peaked at age 14, resulting in a "break" from reality. This was the beginning of many hospital stays and a challenging journey to find out the cause. In the end, it was concluded that our daughter had a "dual diagnosis" of bipolar disorder—a mood disorder which resulted in episodes of mania highlighted by impulsive and reckless behaviour—in addition to her disability, all of which created one crisis after another.

As parents, we went through a feeling of utter helplessness. The hospital system tried to do its best, but we were offered band-aid solutions (probably because they were hampered by budget restraints and limited space). Though the level of care was good during emergencies, there was a recurring mantra of "patch her up and send her out until the next time." As parents, we really hoped for a lasting solution outside of initial crisis intervention. We found doctors to be hard pressed for time to provide a course of action for family caregivers beyond intervention, and they ultimately left it to us to find a solution on our own. We felt then, as we continue to feel now (for all other parents who are faced with such situations) that there needs to be a better process that connects hospitals, caregivers, family doctors and patients with a focus on long-term intervention, thereby reducing the need for emergency hospitalization.

Our daughter is now 26 years old. She has struggled to be “normal.” In my experience, becoming the primary advocate for my child has been the best approach to creating a long-term support system. Admittedly, it requires unwavering and long-term commitment to stick to the plan. As a parent, I discovered this on my own, but it would have been extremely helpful to have had a primer to point me in the right direction instead of having us travel down many blind alleys in search of a livable solution.

There has been a light at the end of the tireless stream of blind alleys. Today we have built a “life team” of professionals for our child. The team comprises a general practitioner, a psychiatrist and support workers, as well as job placement counsellors and housing support. I am happy to say my daughter’s situation has improved significantly and she continues to be stable and is making great strides. She is quite remarkable and has taken the initiative to improve her life and future. She lives independently, manages her own daily affairs, is gainfully employed in a part-time job, seeks to continually learn (she is currently taking guitar lessons) and generally feels she has a pretty normal life.

None of this would have been possible without the assistance of her life team, but more importantly, it was her burning desire to make a better life for herself that turned the tide. She has exceeded all of the medical community’s expectations because she chose to set the bar high and because she had true believers on her side. In the end the expectations that counted were hers, not those of others.

Though she will continue to have challenges throughout her life, my daughter has emerged from the tunnel after 12 long years. This is only the beginning for her.

So I ask myself today: are the dreams and desires we had for her the day she was born being met? They are most certainly being fulfilled each day she walks along her life’s journey. And as a parent, I look forward to sharing in her future successes every inch of the way.

It takes a village to raise a child . . . but it can be done!

The expression “It takes a village to raise a child” has been used so often that it has become a cliché, but for our family, it has been our credo—our guiding light. There are three lessons I hope people take away from our experience:

- Do not put all of your eggs in one basket—do not rely on just one or two resources.
- Build a village of professionals, programs, services, agencies and volunteers. Put your name on many wait lists.
- Plan for the future. When your child is a toddler, plan for their school years. When your child is elementary school age, plan for the teen years. When your child is a teenager, plan for adulthood.

Family stories

Our son Joseph, who is now turning 21, has a primary diagnosis of autism, but as is so often the case with people with autism spectrum disorders (ASD), over the years his diagnosis evolved into multiple diagnoses, and with each new challenge, our “village” of agencies, volunteers, programs and services grew. I share our story and a “village” of resources that other families may find helpful and that may sustain their hope for the future of their children.

Early development resources

As is the case with so many people with ASD, Joseph’s early development was fairly typical. He reached his early milestones of first words, first smile and crawling and walking at a typical age. But when he was 2 1/2 years old, he became more withdrawn and was not stringing words together. He had a global assessment and we faced the reality that our beautiful blue-eyed toddler with the ringlet curls and sweet smile had a diagnosis of pervasive developmental delay (PPD)—basically a catch-all term when there is a global delay. While it was very difficult to accept a label, early diagnosis is critical in order to access services. At the same time, we never let the label define or limit Joseph.

Preschool and early primary resources

These were the days before applied behaviour analysis and intensive behaviour intervention, but even in those days, we were instructed to keep Joseph engaged all of his waking hours so he would not retreat into his silent world. At this point, we began to build our village. We enlisted the help of a good “case manager” employed by the school, the first of many and a key partner in advocating for Joseph. We entered him in special school programs, parks and recreation programs, therapeutic horseback riding, and camps and vacation programs. We placed him on every wait list—for skiing, for speech therapy, for assistive communication devices, even a person we called our “toilet training lady,” part of a government program to assist with toilet training. In the days before iPads, our son had his own touch-screen computer. We made sure to plan our weekly family outings to include his interests. In terms of medical care, we enlisted the care of an excellent developmental pediatrician. Her words of wisdom guide me as a parent and advocate: “Always try to get into your son’s mind—how is he experiencing the world? What is he thinking?”

Junior elementary school resources

At this point we thought we had it all figured out—then Joseph hit early puberty. His anxiety increased; he developed tics; and our good-natured, good-humoured charming boy began to have rages and meltdowns. At this point, our village became a city. As a family, we had to admit to ourselves that we needed to access more assistance and medical specialists. We signed up for respite volunteers and programs. We brought onside a behaviour therapist, sibling supports for our other younger children and a pediatric neurologist and psychiatrist. The diagnosis evolved from PDD to ASD, as

well as Tourette's syndrome. Reluctantly, we started Joseph on medications. Our house became a revolving door of volunteers and professionals.

High-school resources

Again, we thought we had reached a status quo. Again our village grew. As Joseph entered his high-school years, his anxiety was accompanied by agitation, aggression and self-abusive behaviour. He often refused to sleep, eat or speak. He was hospitalized on several occasions. A new diagnosis—obsessive compulsive disorder (ODC)—was made, and some new medications were added to Joseph's cocktail of medications.

We had to face the very difficult reality that Joseph was not thriving in our home and that we were exhausted. We had all reached a breaking point.

In the moment, it seemed like the worst case scenario. It never entered our minds that Joseph would be in a group home at the tender age of 16. However, it was the biggest blessing that over the years we had accessed so many services that we could honestly say we had tried everything and that at this point we had no recourse other than to place Joseph in a group home. To ease the transition, we accessed crisis intervention services, the school autism team and a therapeutic school program. Our village once again exponentially increased to include teams of social workers, medical professionals and transition teams, even the provincial ombudsman to ensure we could access all the resources we needed.

Where are we now? Entering the adult sector

While our family has had many challenges, we have also had many blessings. For one thing, our village has included many "angels"—amazing professionals and dedicated volunteers whom we would not have encountered were it not for Joseph.

We have had to accept that Joseph is not the same easygoing person he was as a toddler. He still has his moments. However, with the help of many interventions, he has regained much of his level of functioning, his humour, sociability, pride in his accomplishments and his keen interests, such as music and computers. All of those programs and services we accessed over the years continue to anchor Joseph and help him define himself.

Joseph is graduating from high school soon. Our village will expand once again to include a team that is part of a dual diagnosis program to ease Joseph's transition into the adult sector. We will continue to have to research and advocate so Joseph can access programs and resources to maintain his quality of life. We continue to ask ourselves, "How is Joseph experiencing the world and what is he thinking?" We continue to grow our village.

Resources

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Resources

WEBSITES

Autism Ontario

<http://autismontario.com>

Canadian Association for Research and Education in Intellectual Disabilities (CARE-ID)

www.care-id.com

Care to Know Centre (Saint Elizabeth Health Care online community)

www.caretoknow.org

Centre for Addiction and Mental Health (CAMH)

www.camh.ca

Community Living Ontario

www.communitylivingontario.ca

Community Networks of Specialized Care

www.community-networks.ca

ConnexOntario Mental Health Help Line

www.mentalhealthhelpline.ca

Developmental Services Ontario

www.dsontario.ca

FASD One: Fetal Alcohol Spectrum Disorder Ontario Network of Expertise

www.fasdontario.ca

National Association for Persons with Developmental Disabilities and Mental Health Needs (NADD)

www.thenadd.org

National Institute of Mental Health

www.nimh.nih.gov

NADD Ontario

www.dualdiagnosisontario.net

Psychosis Sucks!

www.psychosissucks.ca/epi

Surrey Place Primary Care

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

BOOKS

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Tilton, A. (2004). *The Everything Parent's Guide to Children with Autism: Know What to Expect, Find the Help You Need, and Get through the Day*. Avon, MA: Adams Media.

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Resources

APPENDIX: Websites referenced in this guide

American Association on Intellectual and Developmental Disabilities
www.aamr.org

Autism Ontario
www.autismontario.com

Caregiver Health assessment
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx

CaretoKnow Centre
www.caretoknow.org

Centre for Substance Abuse Prevention
www.centreforsubstanceabuse.ca

Community Living Ontario
www.communitylivingontario.ca

Community Networks of Specialized Care
www.community-networks.ca

ConnexOntario Mental Health Helpline
www.mentalhealthhelpline.ca/Search/AdvancedSearch

Developmental Services Ontario
www.dsontario.ca

Ensemble:
www.ensembleunderstands.com

Extend-a-Family
www.extendafamily.ca

Family Alliance
www.family-alliance.com

Fetal Alcohol Spectrum Disorder Ontario Network of Expertise
www.fasdontario.ca/cms/resources/support-groups

Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities
www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.asp]

Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities tool

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx.

Heep Chi Association

www.heepchi.com

Hospital passport (aapnj)

www.aapnj.org/uploadfiles/documents/2011/Health%20Passport%20English.pdf

Hospital passport (EasyHealth)

www.easyhealth.org.uk/sites/default/files/Hospital%20passport%20-%20JBC.pdf

How Resilient Are You

www.resiliencycenter.com

Informed Consent in Adults with Developmental Disabilities tool

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

KE dual diagnosis page

knowledgex.camh.net/amhspecialists/specialized_treatment/dual_diagnosis/Pages/default.aspx

Lighthearted concepts

www.lightheartedconcepts.com

Medications (University of Birmingham)

www.ld-medication.bham.ac.uk/2erg.pdf

Mental Health Medications

www.nimh.nih.gov/health/publications/mental-health-medications/index.shtml

MyHealthPassport (Sick Kids)

www.sickkids.ca/myhealthpassport

My Therapy

www.mytherapynet.com

NADD

www.thenadd.org/pdfs/resourcesforfamilies.pdf

NADD Ontario

www.naddontario.org

Ontario Program Standards for ACT Teams

www.health.gov.on.ca/english/public/pub/ministry_reports/mentalhealth/act_standards.pdf

Primary Care of Adults with Developmental Disabilities

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

Resources

Psychotherapeutic Medications 2008

www.attcnetwork.org/regcenters/productDocs/5/Psychotherapeutic%20Medications%202008.pdf

Resiliency Center

www.resiliencycenter.com

South Asian Autism Awareness Centre

www.saaac.org

Self-Compassion, Dr. Kristin Neff

www.self-compassion.org

Supports and Services for Persons with a Dual Diagnosis: A Resource Manual for York Region Families (York Support Services Network

www.yssn.ca/resources-publications/

The Forensic Mental Health System in Ontario: An Information Guide

knowledgex.camh.net/amhspecialists/resources_families/Documents/forensic_guide_en.pdf

The Resiliency Quiz

www.resiliency.com/htm/resiliencyquiz.htm

The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act [2008

www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_08s14_e.htm

The Sibling Support Project

www.siblingsupport.org

Today's Visit form

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis

[www.fasdcenter.samhsa.gov/documents/WYNKDiagnosis_5_color\]A_new.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKDiagnosis_5_color]A_new.pdf)

United Families of Eastern Ontario

www.ufeo.ca

Using Emergency Services

knowledgex.camh.net/videos/Pages/dd_using_er2012.aspx

What to Expect When You Go to the ER

knowledgex.camh.net/videos/Pages/dd_expect_er2012.aspx

Youthlink Parent Group

www.youthlink.ca