

# The other dual diagnosis: Developmental disability and mental health disorders

Several case histories illustrate the challenges faced when caring for patients with cognitive disabilities and co-occurring mental illness.

**ABSTRACT: The term “dual diagnosis” is often used to refer to patients with substance abuse disorders and mental illness. However, it is also used for children and adults who have developmental disability along with co-occurring mental illness and behavioral difficulties. When someone with developmental disability presents with behavioral difficulties it can be challenging to determine the underlying cause of such difficulties. Because of their cognitive and adaptive disabilities, individuals with developmental disability are less likely to have developed appropriate coping skills for a variety of stressors. Also, many people with developmental disability have limited verbal skills, so pain and discomfort caused by medical problems may be expressed as physical aggression. Physicians can provide better care for their patients with dual diagnosis by being familiar with mental health services currently available and by considering some diagnostic challenges and gaps in services illustrated here by several case histories.**

**T**he term “dual diagnosis” is generally used to refer to patients with substance abuse disorders as well as mental illness. However, there are others this term is used for: children and adults who have lifelong developmental disorders along with co-occurring mental illness and behavioral difficulties.

The term “developmental disability” (DD) has both a narrow and a wide definition. In this article we use the term narrowly to refer to children and adults with mental retardation according to *DSM-IV* (IQ less than 70, onset before 18, and concomitant adaptive living skills deficits). A wider definition of DD would include children and adults with developmental disorders such as autism and FASD, with significant impairment in adaptive living skills, but whose IQ is greater than 70.

Determining whether a medical problem or a mental health problem is the underlying cause of behavioral difficulties in this patient population can be challenging.<sup>1</sup> Individuals with developmental disability are less likely to have developed appropriate coping skills for a variety of stressors because of their cognitive and adaptive disabilities. Also, medical complications may present as challenging behaviors. Because many people with

developmental disability have limited verbal skills, pain and discomfort may make them physically aggressive. In addition, we know there is an increased prevalence of mental illness and dementia in people with developmental disability compared with those in the general population.<sup>2</sup>

Although specialized outpatient and inpatient mental health services are available in BC along with community health and social services, there continues to be significant gaps

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in services for those with DD, particularly when these patients require crisis response, more acute care, or increased social supports.

### Services available

This is a new era. The last institution for adults with DD in BC was closed only 11 years ago. Community health services are still trying to find a balance between accessing generic services when appropriate, and developing specialized resources when applicable and when possible. However, there seems to be little planning in place to prepare for a new generation of children and adults with DD who have lifelong needs, including many with autism spectrum disorders, complications of prematurity, and fetal alcohol spectrum disorders. BC has closed the institutions, but is still grappling with providing appropriate and sufficiently funded community-based services for mental health needs. Appropriate planning will require active collaboration involving families, Community Living BC (CLBC), and various government ministries and other agencies, including the Ministry of Health (MOH), the

Ministry of Children and Family Development (MCFD; the Provincial Health Services Authority), and individual health authorities (see **Table** for a glossary of agency names and terms related to care for DD patients).

### Outpatient mental health services

In BC, specialized community mental health services for people with developmental disability are provided by each of the five regional health authorities as part of their mental health and addiction services. There is only one team per health authority (HA). These developmental disability mental health (DDMH) teams are multidisciplinary and consist of psychiatrists, mental health nurses, behavioral therapists/psychologists, and neuropsychologists, and see those aged 14 years and up. These teams were started in the early 1990s when the institutions for those with DD were being downsized and closed in BC, primarily to provide mental health care for those adults with DD being resettled in the community. Team staffing levels, however, have been considerably less than adequate to meet the ongoing and increasing demands for service. Because of the shortage of psychiatrists specializing in developmental disability, mental health nurses and behavioral therapists frequently take on more responsibility and act as a liaison between the patient, the family/caregiver, the CLBC representative, and the psychiatrist.

### Inpatient (tertiary) mental health services

The Provincial Assessment Centre (PAC), located in Burnaby, is a 10-bed mental health inpatient service specifically for people with developmental disability (aged 14 and up) run by Community Living BC. CLBC is a provincial Crown authority that pro-

vides funding for community social support services to children, youth, and adults with DD. The DDMH teams have no involvement in the running of this facility and PAC has its own specialists. There are no dedicated psychiatric beds for people with DD in any of the health authorities. Some question whether CLBC should run a mental health facility such as PAC, which is rather isolated from mainstream health and mental health services. PAC is not an acute care resource and does not take emergency admissions. PAC provides assessment, short-term treatment, and stabilization, with a maximum 90-day admission. There tends to be a waitlist of weeks or months for admission to PAC. The 90-day maximum stay rule in PAC is often problematic, as psychiatric symptoms in this client population may require extended observation and treatment. Frequently, numerous medication trials are required, behavioral approaches need to be developed, and clients often become worse before they get better; treatment goals cannot always be accomplished within a 90-day admission. Unfortunately, there is no other option in BC for individuals with DD who require psychiatric treatment for longer than 90 days.<sup>3</sup>

### Community health services

The Health Services for Community Living (HSCL) teams were also started during deinstitutionalization and are based in each health authority. They may include nurses, occupational therapists, physiotherapists, dental hygienists, and nutritionists whose mandate is to provide adults with DD with health care or to help them access health care resources. Because of the special needs of these patients, family physicians may hesitate to accept someone with DD in their practice. HSCL staff can work with family

**Table. Glossary**

CLBC	Community Living BC
CYMH	Child and Youth Mental Health
DD	developmental disability
DDMH	Developmental Disability Mental Health
DM-ID	Diagnostic Manual—Intellectual Disability
HA	health authority
HSCL	Health Services for Community Living
MCFD	Ministry for Children and Family Development
MOH	Ministry of Health
PAC	Provincial Assessment Centre
PHSA	Provincial Health Services Authority
SIB	self-injurious behavior

practitioners and provide support to patients and their families or caregivers regarding treatment plans. Hospital emergency departments and general medical or surgical wards may be challenging environments for some with DD, and the presence of a support person or an HSCL nurse liaison may allow for more successful treatment. However, the acceptance by the hospital of the support person's role is necessary for this success. There are limited funds in each health authority for in-hospital support for people with DD. Hospital staff need to be made aware of this available but limited funding.

### **Community social services**

Traditionally, case management was provided by the social workers within the Community Living section of the Ministry of Child and Family Development, whose responsibilities included community-based housing, respite services, and day programs for adults (and children and youth) with DD.

This responsibility was taken over by CLBC in July 2005. CLBC is now the government agency with funding responsibility for housing and day programs and other such community supports for children and adults with DD.

Since this changeover, case management has been substantially reduced or eliminated. The part once played by social workers has now been taken over by facilitators and analysts, whose roles are still evolving. These complex changes have caused strain throughout the system for patients, families, caregivers, and for partners such as DDMH and HSCL. Families and support workers frequently do not have the training or the knowledge of available services, nor the expertise to sort out which combination of services is most beneficial to their family member or pa-

tient. In some cases, the caregiver or support services are not an ideal fit for the patient. This is not always recognized by the caregiver/support services, and there may be a tendency to ask for medication to treat the patient's behavioral difficulties. Traditionally, the social worker would have been in a position to identify this "poor fit." Indeed, it is not uncommon for behavioral difficulties to vastly improve without new or increased medications if the patient's environment is optimized, particularly if there is no clear Axis I psychiatric disorder.

The issue of unfamiliarity has also begun to affect services provided by CLBC, now that case management services are no longer provided. Now patients, their families, and their support services contact the CLBC intake staff, as they do not usually have any one staff member identified as their contact person. A facilitator may continue to be involved for one issue on a time-limited basis, but not necessarily for the next issue, making the services provided to the patient, family, and caregivers more disjointed.

### **Mental health services for youth under age 14 with DD**

Developmental Disability Mental Health Services historically have only been funded for those aged 14 years and older, leaving those under 14 underserved when they require psychiatric services. The BC Children's Hospital neuropsychiatry unit sees some of these children, but the majority of services for these children fall under the jurisdiction of the local community MCFD Child and Youth Mental Health (CYMH) centres. Unfortunately, these CYMH centres typically do not have the expertise to support children with DD, and these families are frequently told that they cannot be helped. There have been two recent developments in this area. CYMH has provided new

funding to all of the DDMH teams in BC for enhanced services for youth with DD, and specific DD training for CYMH clinicians has been planned for 2008.

### **Gaps in services**

There are too few clinicians with training and expertise in DD and not enough specialized mental health inpatient and respite services. These service gaps put many dual diagnosis patients at risk, as the following case histories illustrate.

### **Lack of clinicians with training and expertise in DD**

When treating patients who already have mental health issues, there is a general tendency to initially attribute physical symptoms to psychiatric illness. Some people with DD may not be able to describe their physical distress, while others, though verbal, may not be considered reliable in their self-report (Cases 1 and 2). In other cases, a patient may have an Axis I psychiatric disorder that requires treatment (Case 3).

**Case 1:** "Sheryl" is a 40-year-old woman with a mild to moderate DD, poorly controlled diabetes mellitus, and a history of major depressive disorder. When Sheryl has major depressive episodes, she presents with increased physical and verbal aggression targeting care home staff and other residents. Her depression has been managed well in the past with antidepressants and her aggression has been managed well with behavioral interventions from skilled staff. When she presented with a sudden deterioration marked by lethargy, apathy, social withdrawal, hypersomnia, weakness, shortness of breath, and increased physical aggression, staff requested increased support from CLBC in order to manage Sheryl's needs and the needs of other residents.

Support was not readily available, so conditions for the other residents deteriorated. In addition, Sheryl could not immediately undergo the investigations she needed. Given her level of physical aggression, the hospital was reluctant to admit her because they could not ensure the safety of staff and other patients without more support. Eventually Sheryl was diagnosed with bilateral pleural effusions and right-sided heart failure.

Sheryl's case is an example of behavioral problems resulting from medical problems.

**Recommendation:** Establish a dedicated, rapidly accessible fund in CLBC to provide sufficient support for such circumstances. One extra staff member in the home was all that was required. An alternative would be to establish a specialized facility under the health authority for investigation of such patients who are not in crisis but who are overwhelming their community resources and require investigations into underlying medical, psychiatric, and psychosocial factors. There is an urgent need for such a facility in BC.

**Case 2:** "Laura," in her 20s, has mild DD and lives in a semi-supported placement. Over approximately 2 months she developed progressively lower energy, hypersomnia, weakness, weight gain, and a depressed and anxious mood that she described as subjectively different from previous periods of depression. Her family physician reportedly examined her but felt the problem was psychiatric. Her placement support workers took her to the emergency department of the local hospital; after drawing blood, the ER doctor sent her home. When she presented to her DDMH team and a history was obtained, a test to measure her thyroid stimulating hormone levels was ordered and she was found to be hypothyroid.

Laura's case illustrates how underlying health needs can be missed in the DD population.

**Recommendation:** Improve training on DD for medical students, family practice residents, and general physicians.

**Case 3:** "Ian" has profound DD. He had a 3-month period of severe self-injurious behavior (SIB) characterized by frequently and repeatedly punching his face with his fists. This caused deep, ulcerated lesions that became infected. Systemic inquiry revealed that a long-term resident in Ian's group home had died in the past year and that this person and Ian had been close friends for many years. Ian had not engaged in any SIB for the previous 10 years. Systemic inquiry also revealed significant symptoms of depression, including disturbances in sleep and appetite and increased agitation. Ian appeared to have little motivation to engage in previously enjoyed activities, and was more "grouchy" according to staff. A physical examination by Ian's GP indicated no obvious source of pain in his facial region and a dental examination was scheduled.

The team behavioral consultant started tracking Ian's SIB in an effort to identify triggers. However, the behavior was so frequent that it was difficult to assess. Eventually major depression with complicated bereavement was diagnosed. An SSRI antidepressant was added to Ian's longstanding antipsychotic medication, and art therapy was started.

As his mood improved, his SIB became less frequent. He was encouraged to self-restrain his arms and the group home staff were guided to help all the residents deal with grief and loss.

Ian's case illustrates how behavioral problems can result from mental illness. Irritability is accepted by *DSM-IV* as a symptom of depression in chil-

dren, but not in adults. *The Diagnostic Manual—Intellectual Disability (DM-ID)*, however, does recognize irritability as a depressive equivalent in this population.<sup>4</sup>

Ian's case also reminds us that bereavement and grief are part of the human experience and those with DD are as vulnerable to this stressor as the rest of us. Staff and caregivers need to be sensitive to the effects of this life stress on patients and provide appropriate support and understanding.

**Recommendation:** Provide in-service and training in mental health and DD for support workers.

#### **Lack of specialized mental health inpatient and respite services**

In BC all three long-stay institutions for people with DD were closed by 1996, and the residents were placed in the community.<sup>3</sup> Willow Clinic (now the Provincial Assessment Centre) adjusted its mandate so that people with DD needing subacute psychiatric assessment and treatment could not stay more than 90 days. This restriction was imposed because of past problems with long-term patients who could not find community placements and thus could not be discharged—a situation that prevented new admissions.

Previously, there were also two beds at St. Vincent's hospital that were reserved for patients with DD, but the hospital actually averaged four patients with DD from across British Columbia at any one time. This access disappeared when the clinical director at St. Vincent's hospital changed in the late 1990s. Clients with DD also had some access to beds in the UBC neuropsychiatry program until a few years ago, when the Provincial Health Services Authority (PHSA) blocked admission of clients with DD. Similarly, Riverview Hospital now refuses

admission to patients with an IQ less than 70. As this is the only facility that accepts violent psychiatric patients who cannot be managed in other hospital settings, the lack of access for those with an IQ below 70 may result in unsafe conditions in the community and the community hospital, for the patient as well as others.

Patients with DD and complex mental health needs are thus caught in a “turf war” between PHSA and CLBC. Clearly, we need tertiary mental health facilities jointly funded by PHSA and CLBC. CLBC also needs to recognize that persons with DD and complex tertiary needs require specialized resources and that the health sector cannot be expected to fund these specialized resources alone.

Currently there is no acute mental health crisis resource for people with DD outside of the usual emergency and inpatient psychiatric units, where those with DD have traditionally done poorly because of their unique needs (Cases 4 and 5). There is also no intermediate resource for patients who are no longer in need of acute care but who are not yet ready to return to a community home (Case 6). Finally, there is a lack of respite services for patients and their caregivers (Case 7).

**Case 4:** “Ted” is a 27-year-old man with DD and bipolar disorder. After he developed florid manic and psychotic symptoms, he required admission to ensure his own safety, as well as the safety of others. PAC was unable to admit him on an urgent basis as this is not PAC’s mandate. He was treated on a general inpatient hospital psychiatry unit, where his condition deteriorated despite medication. Part of his anger and aggression occurred because he was unable to understand that he could not have the same privileges as the non-DD patients. After 6 weeks he was transferred to the Provincial Assessment Centre.

**Case 5:** “Leo” is a 27-year-old man with moderate DD (IQ approximately 40) and autism. Because of his autism, Leo has a tendency to become stuck on certain rituals and needs to complete them in a certain order. Leo may perseverate on rituals for hours and sometimes days at a time. During these periods, anyone coming into Leo’s personal space or attempting to engage him is likely to be physically assaulted. Because Leo has low verbal skills, even experienced, skilled staff may not be able to predict an aggressive episode. Leo requires structure and predictability in his life, but this is not generally possible in this home, where there are others with different needs and only a limited number of staff.

Outpatient pharmacotherapy as well as attempts to adapt Leo’s environment were not successful. Eventually, he was admitted to PAC, where few of his aggressive outbursts were seen, probably because of the structure and high staffing ratio. After 3 months he was discharged, but the pattern of repeated unpredictable violent outbursts continued. Leo’s aggression substantially worsened after his thioridazine was stopped when the drug was no longer available because of an advisory and withdrawal by Health Canada.

Leo’s case illustrates two significant problems. First, he needed a long-term care home with highly trained staff who understand autism well, but the DD treating mental health teams could not provide such a facility because the funding for housing comes through CLBC. Second, the withdrawal of thioridazine by Health Canada occurred without consultation with psychiatrists working in this field, who have known for years that some patients are unable to tolerate its discontinuation or change to another antipsychotic medication.

**Recommendation:** Make funding available to or within each health authority for specialized housing for such complex individuals (similar to the units available for adult neuropsychiatry). Also, have health policy-makers provincially and nationally consult with expert clinicians in the DD field when considering decisions that have implications for the DD population.

**Currently there is no acute mental health crisis resource for people with DD outside of the usual emergency and inpatient psychiatric units, where those with DD have traditionally done poorly because of their unique needs.**

**Case 6:** “John” is a 20-year-old man with severe DD and autism. He has always been hyperactive and had a tendency to jump up and down and make loud whooping noises when excited (happy or unhappy). In the last 2 years, his hyperactivity has increased and he has developed symptoms consistent with mania (less need for sleep, increased sexual drive, more vocalizing). Pharmacotherapy as well as behavioral management had been minimally effective. After John ran into the street, was nearly run over, and then attacked a staff member, he was admitted to the local emergency department. However, the stress of being in the confined and busy space of the acute psychiatric unit made John more agitated. Fortunately, the psychiatry resident on call that night knew John from a previous DD residency rotation, and knew that he responded positively to having his

hair rubbed when he was upset. The nurses were less apprehensive about John after this; however, because of his tendency to bolt and run into any room at any time, staff felt he needed to be in seclusion. Unfortunately, this reminded John of punishment he had previously experienced and he became inconsolable. He was not deemed suitable for the psychiatry inpatient unit and was discharged the next day back to his group home, still agitated and difficult to manage.

John's case illustrates how mainstream mental health clinicians may lack specific expertise and experience in working with individuals with DD, and may not recognize mental health symptoms as being above and beyond the patterns associated with their DD.<sup>3</sup> John was perhaps not appropriate for the inpatient unit of this hospital, but he certainly wasn't calm enough to return to his community home. Yet because of an absence of step-up/step-down beds, there was no alternative.

**Recommendation:** Provide a range of options for patients with DD needing intermediate care, including crisis stabilization beds, step-up/step-down beds, longer stay resources for patients who require longer specialized treatment in hospital than PAC can offer, and specialized psychiatric respite homes in the community. Resources providing care between hospital and community with skilled staff familiar with this population as well as mental health are crucial. Transferring PAC to the Ministry of Health rather than having it remain under CLBC/MCFD should also be considered.

**Case 7:** "Bev" is a woman with moderate DD in her mid-40s. She had lived with one caregiver for approximately 5 years. During this time, the caregiver found Bev's behavior very difficult, and complained of her irritability, trouble sleeping, and verbal

aggression. Bev was prescribed three different medications for depression and anxiety without success and endured various side effects. It was not until she finally moved into a new home that Bev was able to explain that she had not gotten along with her previous caregiver. Bev did not require any medication at her new home, and follow-up visits confirmed that she got along well with her new caregiver. Of note, there were no complaints of irritability, difficulty sleeping, or aggression in the home.

Bev's case illustrates how patients with DD respond to different environments and how there is a significant lack of respite services for persons with DD and their caregivers. Many clients live in "home sharing" (formerly called "proprietary care"), which can best be described as adult foster care in family homes. Many clients also live in group homes. Staffing these homes is frequently an issue. Because of inadequate financial remuneration and the demands of the job there is frequent turnover of group home staff. Thus, patients are often exposed to newly trained and inexperienced staff, as well as frequent changes in staff, which can be anxiety provoking. Some group home staff do not adequately administer and monitor medications, and some staff may not be trained in giving medication or monitoring side effects. This lack of attention to medication needs can contribute to significant decompensation for those clients with major Axis I disorders or make it challenging to determine side effects from treatment failure.

**Recommendations:** Have CLBC re-establish case managers for complex cases, and provide adequate respite services both for crises and for planned respite for families and other caregivers who require further support.

## Conclusions

Working with patients who have developmental disability and mental health needs and their caregivers is tremendously rewarding. Often, simple interventions can result in significant quality of life improvements, and helping families and patients realize their full potential is extremely gratifying. However, although specialized outpatient and inpatient mental health services are available to those over the age of 14 years with DD, there continues to be significant gaps in services, particularly for those clients who require crisis response, more acute care, intermediate care, or increased social supports. These clients are among the most vulnerable members of society and increased cohesiveness and comprehensiveness of services are required.

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## Competing interests

None declared.

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