Guidelines for Managing the Client with Intellectual Disability in the Emergency Room
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Prepared by Elspeth Bradley and the Psychiatry Residency Year 1 (PGY1) Intellectual Disabilities Psychiatry Curriculum Planning Committee University of Toronto
Preface

Since 1995, the psychiatry residency curriculum at the University of Toronto has included systematic teaching in intellectual disabilities. This topic is introduced to residents during the first six months of their training in two core curriculum half-day seminars. At this stage, the residents are new to psychiatry. They are particularly anxious about how to manage psychiatric emergencies, and for many, this is their first exposure to persons with intellectual disabilities. In their feedback to us, residents have consistently asked for more information on how to manage persons with intellectual disabilities when they are brought to the hospital in crisis.

There are few specialized mental health services for persons with intellectual disabilities in Ontario. Unfortunately, the first direct clinical experience the resident has with a person with intellectual disability is often in the emergency room. This encounter, positive or negative, is likely to influence the psychiatry resident's attitude toward persons with intellectual disabilities as a group. It is also likely to influence the resident's inclination toward further professional involvement with this population.

In writing these guidelines, we have therefore tried to address several issues that we feel, if not addressed, may create anxiety for health care providers, and lead to less than optimal intervention when treating persons with intellectual disabilities in crisis.

We start by outlining ways to optimize the clinical encounter. We then provide a framework for understanding and assessing the complex medical and mental health issues that often arise for
persons with intellectual disabilities. Lastly, we provide a systematic way to evaluate how best to approach treatment and triage. Our hope is that these guidelines may contribute to a better outcome both for the client who comes to the emergency room and for the resident (or other health care worker) providing care.

These guidelines have been prepared by members of the Intellectual Disabilities Psychiatry Curriculum Planning Committee.* Members of this multidisciplinary committee have been involved in teaching first-year psychiatry residents over the past seven years. We would like to thank all those residents who attended the core curriculum seminars on intellectual disabilities in their first year and brought to our attention their immediate concerns in working with this population.

The committee is also indebted to the following individuals who kindly reviewed earlier drafts of the guidelines and made helpful suggestions for improving the manuscript: Dr. Carol Coxon, (fourth-year psychiatry resident), Dr. Laura McCabe (third-year psychiatry resident), Dr. Chris McIntosh (first-year psychiatry resident), Dr. Nadine Nyhus (psychiatrist, Dual Diagnosis Program, Centre for Addiction and Mental Health (CAMH), Toronto), Dr. Martin Breton (family physician, Dual Diagnosis Program, CAMH, Toronto), Mr. Neill Carson (Manager, Dual Diagnosis Resource Service, Toronto) and Ms. Brenda Greenberg (Supervisor, Special Projects, Griffin Community Support Network, Toronto).

Finally, we would like to express our appreciation to publishing developer Caroline Hebblethwaite and editor Diana Ballon from the Centre for Addiction and Mental Health for their collegial assistance in helping us prepare these guidelines for publication.

As we plan to update these guidelines on a regular basis, we would greatly appreciate your feedback. Please send any comments and suggestions to:

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Assessment

1.1 Optimizing the clinical encounter

You should be aware of the following:

Persons with intellectual disabilities vary greatly in their ability to understand and communicate their needs, discomforts and concerns. You will therefore need to adapt your approach to each client’s level of functioning and understanding.

If the client is behaving disruptively, begin by meeting briefly with the caregivers to inquire about their client’s level of functioning and to get advice about how best to meet and interact with their client. Find out about any circumstances that might be specifically upsetting for that individual (e.g., being asked too many questions; being in a noisy/busy environment; someone moving too close to them; seeing reflecting surfaces, such as eyeglasses).

*Intellectual disability is sometimes referred to as developmental disability (Ontario), learning disability (UK) or mental retardation (DSM-IV-TR, 2000).
Many individuals may be unable to communicate verbally but will be aware of non-verbal behaviours in others and are often sensitized to negative attitudes others have toward them. Some individuals depend on others to help modulate their emotions and will quickly pick up fear and anxiety in you. A warm, accepting, calm and reassuring attitude will help the client feel more relaxed.

The ER is generally a strange and unfamiliar environment for anyone. For persons with intellectual disabilities, the experience may be particularly scary because they may not understand what is happening around them. Getting to the ER may also have been traumatic, both for the client and his or her family. Waiting can be anxiety-provoking and contribute to behavioural disturbances. Take a moment to explain to the client and his or her caregivers the reason for the wait. If the wait is longer than you expected, check in from time to time to reassure the client. This will contribute to a more effective interview.

Always check to see if this is the client’s first visit to the ER and whether there is previous information on the client. If the client has been to the ER before, find out what worked and what did not work.

Find out if a proactive crisis plan has already been set up by caregivers in the community and whether caregivers have brought a letter from the client’s physician outlining this plan.

Remember that appearances may be deceptive. Individuals with intellectual disabilities may appear to be hearing impaired or mute when this in fact is not the case. Overheard comments about them may exacerbate the presenting problems.

Assessing a client with an intellectual disability takes time. Research indicates that the process may take four times longer than the time required for someone without such a disability.

**Practical tips on conducting the interview:**

- Try to make the individual as comfortable as possible.
- Familiarity helps. Suggest that someone familiar to the client (e.g., caregiver) remains present.
- Use suggestions previously identified by the caregiver to help the client be more at ease.
- Encourage use of “comforters” (e.g., Does the individual have a favourite item he or she likes to carry or does the client like to engage in self-soothing, such as rocking or standing?).
- Try to find a quiet spot, without interruptions.
- Try to establish a positive relationship with the client:
  - Be interested in a precious object the client is clutching.
  - Show warmth and a positive regard.
  - Be sensitive to cues and tone of voice.
  - Be aware of any non-verbal messages you are giving that the client may generalize to a previous experience (e.g., Based on past experience, the client may respond idiosyncratically to a head nod or shake, or to your cologne/perfume).
  - Avoid direct questions. The client may experience these questions as intimidating or may just say yes to please.
• If the client seems fearful, give him or her time to size you up.
• Respect personal space.
• Ask permission to proceed prior to any intrusion of personal space, and explain and forewarn the client about what to expect from procedures that may need to be done immediately. Ask caregivers whether protocols have already been established for some procedures (e.g., venepuncture) and follow these. Provide reassurance during the procedure or provide support according to the protocol already established by caregivers.

Find ways to communicate effectively:
• Use simple words.
• Speak slowly.
• Do not shout.
• Pause. Do not overload the individual with words.
• Be sensitive to the individual’s non-verbal cues and adjust your behaviour accordingly. For example, if the client shows fear in response to your approach, consider what might be contributing to this fear (e.g., reflection from your eyeglasses, white coat, stethoscope) before approaching further. Modify your approach as required (e.g., take off white coat, enlist the participation of familiar caregiver).
• Use visuals (e.g., drawings).
• Use gestures.

Remember that persons with intellectual disabilities have a variable and limited ability to interpret their own internal cues and may not be able to give you an accurate picture of their internal state. Involving caregivers who know the individual well may help you to better understand the client’s subjective experiences.

1.2 Biopsychosocial understanding

The psychiatric assessment of the individual with an intellectual disability involves systematically applying a biopsychosocial approach. Expect the presenting problems to have multiple and complex etiological and contributing factors. Be systematic in taking a history. Be sure to assess the influence of causes other than psychiatric disorder for the referral concerns.

The overall goal is to understand contributions from:

1. **medical disorders** (e.g., constipation, toothache, earache, reflux oesophagitis, bone fractures, urinary tract infection, other sources of pain or bodily discomfort)

2. **problems in expectations and supports** as individuals with intellectual disabilities are much more dependent on external structures. Emotional problems often arise when expectations and supports change (e.g., recent move; change in staff: staff turnover can be very high in some group homes; change in daily life schedule, such as start of school/work; change in work activities) or are inappropriate (e.g., unrealistic expectations about completing tasks or travelling independently).

3. **emotional upsets** (e.g., response to co-resident or staff leaving group home, illness in client or significant other, seasonal pattern/anniversary reaction, trauma, abuse or triggers to past abuses). Note that grief can be delayed.
4. **new onset psychiatric disorders and/or ongoing (chronic) psychiatric conditions.** Adjustment, mood, anxiety and post-traumatic stress disorders are the most frequent new onset psychiatric disorders. Autism is the most frequent chronic comorbid psychiatric disorder across the range of functioning. Stereotypies and self-injurious and compulsive behaviours are often seen as chronic comorbid conditions, especially in lower functioning individuals.

In determining the relative contributions of circumstances 1 to 4, as listed above, all the basic areas of inquiry need to be examined: client’s main concerns; caregivers’ main concerns; history of concerns with an emphasis on recent life events and changes; medical history; medication history; allergies; family psychiatric history; personal, developmental and social history.

It is also important to gather more detailed information on the client’s usual level of functioning (baseline) and supports prior to this episode of disturbance. Seek further information about:

- **cognitive functioning** (e.g., reading, writing and math grade levels; school history; results of previous psychological assessments; information about verbal and non-verbal IQ/functioning)

- **adaptive functioning** (e.g., level of independence in daily life skills: amount of support needed around hygiene, dressing, eating and preparing meals; whether the client can initiate his or her own activities, be left safely alone at home and travel independently)

- **communication** (e.g., level of receptive understanding and expressive language)

- **social functioning** (e.g., abnormalities in social response, eye contact, facial expression, the use of gesture to communicate, social initiation and reciprocity that might indicate a comorbid autism spectrum disorder)

- **residential circumstances** (e.g., living with family or in a group home, and level of support in these settings) and

- **daily activity** (e.g., attending school, day centre or other organized activities, and supports in pursuing these).

At the end of this inquiry, you should try to evaluate whether the expectations of the client, and the supports provided, are appropriate given the client’s level of functioning and recent circumstances. For example, are you sure that caregivers understand the challenges the client has to face on a daily basis? (e.g., If the client has a hearing impairment, have appropriate adaptations been made in the client’s physical and social environment?)

In summary, assessing persons with intellectual disabilities involves not only a standard psychiatric assessment, but also a systematic approach designed to identify the contributions of other circumstances to the behaviours of concern.

In the ER, you may only be able to get a superficial understanding in these areas of inquiry, but this may be sufficient to alert you to areas of concern that may be contributing to the problems. These need to be pursued in more detail by the multidisciplinary team once the immediate crisis is past.
1.3 Assessing symptoms and behaviours that may point to a new onset psychiatric disorder and assessing for the presence of ongoing (chronic) psychiatric conditions

It is first important to determine whether there has been a significant change in baseline behaviours and functioning. An episode (or episodes) of changed behaviour can be identified as follows*:

Determine usual behaviour and usual level of functioning (baseline) prior to onset of new disturbance in terms of: self-care, interest/involvement in school, work, play/leisure, social involvement, initiative, level of supervision required.

Determine whether:

a. there has been a change in behaviour outside the range of normal variation for the individual, lasting at least one week and a definite diminution in level of functioning in at least two of the following areas: self-care, interest/involvement in school/work, play/leisure, social involvement, initiative, need for change in supervision/placement

or

b. psychotic symptoms (e.g., delusions, hallucinations, catatonia) are, or have been, present and have lasted at least three days. (Note that it is difficult to diagnose psychotic symptoms in persons with an IQ below 50.)


Provisional psychiatric diagnosis

If the referral concerns or behaviour disturbance meet criteria for an episode of change, then an episode of psychiatric disturbance is established. The next step is to try to match this episode of psychiatric disturbance to a DSM-IV diagnosis. This is frequently difficult, particularly with lower functioning individuals, as subjective experiences needed to establish a DSM-IV diagnosis may be unavailable. From the clinical information available, generate the best provisional psychiatric diagnosis for the episode of psychiatric disturbance.

Comorbid psychiatric conditions

Document baseline self-injurious behaviours, tics, stereotypies, obsessive thoughts and compulsive behaviours, levels of attention, hyperactivity, impulsivity, fears and phobias: these may represent comorbid chronic conditions. Ask whether there have been any changes (i.e., increase in severity and/or frequency) in these comorbid conditions associated with referral concerns/behaviour disturbance. Documenting whether any comorbid conditions are present at this stage is crucial, as these conditions may also arise from the side-effects of medications used to manage the crisis, or to treat an underlying psychiatric disorder.

NOTE: In Ontario, Canada, where the authors work, a person with intellectual disability and mental health disorder is referred to as having “dual diagnosis” while “concurrent disorder” refers to a situation in which the person has both a mental health and substance use disorder.
1.4 CAUTION

1.4.1 Understanding significant changes in behaviour
Significant behavioural changes may result from medical or dental disorders, problems in expectations or supports or emotional upsets. It is important to understand the contribution (if any) of such circumstances to the behaviour disturbance before making a psychiatric diagnosis or concluding that the problem is psychiatric.

1.4.2 Understanding aggression
Aggression is often the reason for the visit to the ER. Aggression of any severity can be the result of any of the four problem areas identified in Section 1.2. The severity of the aggression does not necessarily indicate the seriousness of the underlying cause of the aggression.

1.4.3 Diagnostic limitations in the ER
The ER is not the place to make definitive psychiatric diagnoses; however, provisional diagnoses based on clearly documented descriptions of behavioural changes are appropriate. Indicate clearly on your evaluation/assessment report that the diagnosis is provisional and needs to be reviewed when the crisis has abated. This is necessary as a psychiatric diagnosis made from a brief assessment can stick for years or even decades, and can result in the client being prescribed inappropriate medication for lengthy periods with considerable morbidity. Your recommendations should include a clear outline as to follow-up and re-evaluation of diagnosis and treatment.

1.4.4 Diagnosing psychosis
“Psychotic” behaviour in persons with intellectual disabilities is more often due to their being overwhelmed with life events than to an actual psychotic disorder. For example, due to limited cognitive function at baseline, stress can fragment thought form in a way that may appear psychotic, or the client may express primitive thoughts that sound delusional but actually relate to poor coping more than to frank psychosis. If the client is overwhelmed, treatment involves identifying and attending to the causative life events. However, if it is true psychosis, then antipsychotic treatment is required.

Note that in an emergency situation, medication, along with other interventions, may be required for immediate containment even if no psychosis is diagnosed. It is important therefore that you indicate clearly on your evaluation/assessment report that medication was used to manage the emergency situation (it does not imply a diagnosis), and outline specific plans for follow-up diagnostic appraisal so that the need for medication can be reassessed.
Assessing for a psychiatric disorder in persons with intellectual disabilities presents many challenges and requires obtaining detailed historical information as well as a multidisciplinary approach. This includes drawing on not only the perspective of psychiatry, but also input from other disciplines, such as psychology, communication therapy, behaviour therapy, nursing, genetics and medicine, including neurology.

This diagnostic process can start in the ER but avoid making definitive psychiatric diagnoses at this time. Instead, provide careful documentation of whatever history is available, along with observations of behaviour, and response to interventions in the ER. Ensure that this documentation is available to the team who will provide further psychiatric assessment when the client is triaged. The ER provides an important opportunity to rule out possible medical disorders underlying the behaviours of concerns and also the opportunity to observe the client in a more structured environment.
2.1 Managing the immediate situation

The first priority is to ensure the safety of the client, caregivers and hospital staff consistent with the usual ER procedures. Only then can the assessment continue. Pharmacological or physical restraint may be required as with other clients in crisis. However, the more ER staff appreciate the individual’s level of functioning and unique ways of communicating, the less likely it is that excessive medication or restraint will be needed.

2.2 Ruling out medical (and dental) disorders

The first goal is to identify and, where possible, treat any physical causes of behaviour disturbance. If you are concerned about a possible medical disorder, refer the client for a medical assessment. Also inquire about when the last vision and hearing assessments were done, and about the outcome, as deterioration in sensory functioning can give rise to changes in behaviour.

Refer the client for a dental checkup where indicated or when dental care has not been provided routinely.

2.3 Changing medications

Avoid changing all the client’s previous medications in this emergency situation unless it is clear that these previous medications are contributing to the referral concerns or behaviour disturbance. Resist the temptation to try the latest new medication just because it has not yet been tried for this client. Limit your activities to dealing with the emergency and leave review of regular medication to the client’s usual treatment team. If you feel strongly that an alternative medication regime is more appropriate or should be tried, discuss this first with the regular treatment team.

2.4 Treating a psychiatric disorder

Treatment is generally initiated after the multidisciplinary team does a comprehensive assessment. Once the crisis has been managed and it has been determined that a psychiatric disorder underlies the behaviour disturbance resulting in ER visits, treatment should be initiated in line with the provisional diagnosis. As well, behavioural markers should be identified and these behaviours monitored to substantiate or refute the provisional diagnosis. You will need to discuss with caregivers the behaviours they should start to monitor. For instance, if the provisional diagnosis is a mood disorder, instruct caregivers on how to collect data on such variables as eating and sleep patterns, weight, behavioural equivalents of mood, anxiety and agitation. Such documentation is likely to be invaluable to the team to which the client is triaged. (See Section 3.) A behaviour therapist, available through the developmental service sector, can provide invaluable help with this monitoring.
3.1 Deciding where further assessment and treatment can, and should, take place

Consider what will be most helpful from the client’s perspective (e.g., based on his or her level of functioning and need for familiarity during crises). Also consider the assessment and treatment goals. Appreciate that caregivers are not medically trained and may be apprehensive about giving medications, monitoring side-effects and managing co-existing medical problems.

**There are three main options for further assessment and treatment:**

3.1.1 **Inpatient admission required**

Consider the following when deciding about an acute psychiatric inpatient admission:

1. The client needs to be medically stable. If not, he or she is not suitable for a psychiatric inpatient unit.
2. If the client does not have sufficient expressive and receptive language skills to make his or her needs known, or is not independent in activities of daily living, find out if the referring agency, together with the hospital, can provide additional, needed caregiver support for the client while an inpatient.

3. A behavioural disturbance is frequently the manifestation of a psychiatric disorder, and is an appropriate reason for admitting the individual for further observation.

4. In planning admission, consider how you would handle a client with aggressive, self-injurious or other serious behavioural problems and whether additional support is available, such as, consultation from specialized services. (Also see p. 25 on Success of an inpatient admission.)

5. Propose realistic treatment goals (e.g., clarification of diagnosis, stabilization, review of medications) based on a provisional psychiatric diagnosis. This provisional diagnosis would include identified target symptoms and behaviours that might be monitored in response to treatment interventions.

6. Confirm with caregivers that the client when discharged will return to where he or she was living prior to the ER visit. If this is not possible, ensure that alternatives other than hospitalization have been discussed.

CAUTION: Be aware that some clients might not show any evidence, in the ER or on the inpatient unit, of symptoms and behaviours described by the caregiver. However, when leaving the structured environment of the hospital, these symptoms and behaviours may recur. This is valuable information that may only be obtained through admission.

If the client is admitted to an inpatient bed, consider how the trauma of such an admission can be reduced. Note that being admitted can be especially traumatic for lower functioning clients whose emotional and support needs may be similar to the needs of infants and younger children. Caregivers are often able and willing, with the support of their managers, to spend long periods with the client in his or her hospital environment.

Clinical experience has identified four factors resulting in a poor outcome associated with hospitalization (Sovner and DesNoyers Hurley, 1991):

1. The client is prematurely discharged.
2. The client is overmedicated.
3. The client regresses while on the unit.
4. There is poor communication between the hospital and community caregivers.

Success of an inpatient admission (in terms of meeting the client’s needs and achieving assessment and treatment goals) is usually facilitated by:

- attention to inpatient routines as they affect the client. The client’s caregivers can assist in adapting the hospital routine and procedures to be consistent with those in the client’s home environment (e.g., how and when the client normally sleeps, how he or she engages in hygiene and other activities of daily living and how the client takes his or her medication).
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- **attention to the physical environment** (e.g., locating the client in an end room/bed to reduce his or her distress, and to minimize possible disruption to other clients; ensuring that there is space for caregivers). If the client requires restraint, try to ensure that this is offered in a manner similar to that experienced in his or her home. Community providers should have detailed procedures for that client outlining the use of restraint (physical and PRNs,) and these protocols should be provided to hospital staff.

- **attention to staffing resources** to optimize the inpatient stay. It is wise to find ways to provide consistent nursing staff for the client and to identify nursing staff who can be responsible for liaising with community caregivers.

- **attention to communication**, as good communication with the community team and community physicians (e.g., family physician, community psychiatrist) while the client is in hospital usually contributes to a more comprehensive assessment, a more useful admission, better discharge planning and co-ordination of care, and less likelihood of repeated crises and readmissions.

### 3.1.2 Hospitalization not required but crisis requires an alternative environment

In the event of a situational crisis (e.g., loss of home, caregivers temporarily unable to support client), options for crisis or respite services for persons with intellectual disabilities may be available in the client’s community. Identify these services in the client’s area. Note that not all communities have such options or services.

For individuals from the Toronto area, contact the **Griffin Community Support Network (GCSN)** at **416-222-3563** between 9 a.m. and 9 p.m. seven days a week and the **Gerstein Centre** at **416-929-9897** at other times.

If it is not an immediate crisis, the Gerstein Centre may link you to the GCSN the next day. The GCSN can help clients to access alternative, time-limited (1–30 days) safe beds if they are available in the community or can link you to a central respite resource.

### 3.1.3 Return to home environment with follow-up supports

Identify additional in-home or specialized supports for persons with intellectual disabilities available in the client’s locality.

If the client lives in the Toronto area and can return home, but needs additional supports (e.g., a time-limited contract worker to get through the crisis), contact the **Griffin Community Support Network (GCSN)** at **416-222-3563** between 9 a.m. and 9 p.m. seven days a week and the **Gerstein Centre** at **416-929-9897** at other times.

If it is not an immediate crisis, the Gerstein Centre may link you to the GCSN the next day. If the client is unattached to the system, an interim case manager may be found, if available in the community, through the GCSN.
4.1 Medication

If medication has been prescribed, make sure that this is communicated to the GP or community psychiatrist. If the client does not have a community physician, connect the client to outpatient psychiatric services.

4.2 Referral to specialized services

Specialized assessment and consultation services may be needed if:

- the situation is complex
- several services are already involved
- there is a history of difficulty clarifying a diagnosis or determining effective intervention.

Identify what specialized services are available in the client’s area. For example, individuals from the Toronto area can contact either of the following centres:
Plan for next time

As crises are common for many persons with a dual diagnosis, it is wise to have a proactive crisis management plan. Caregivers should be encouraged to develop such a plan, clearly indicating who to call or what service to contact in response to the issues of concern. For example, for someone who experiences periods of disruptive behaviours, caregivers should have available an escalation hierarchy protocol that indicates how to respond to the individual at each point of his or her behavioural escalation, including when to seek general medical advice. Caregivers will have identified at what point on this escalation hierarchy they need to seek help from the emergency services and when to take the client to the ER. It is often helpful for the caregivers to have a letter written by the community physician that they can take with them to the ER. This letter should briefly outline the psychiatric disorder and treatment being provided. The letter might also suggest preferred ways to manage general crises for that individual, based on past experiences.

Develop and update any existing proactive crisis management plan with caregivers based on the client’s most recent experience in the ER. Encourage caregivers to keep a client binder for ER visits and doctor appointments and to bring this with them to the ER.

Make sure your recommendations from this ER visit are communicated to those supporting the client in the community and those who may be involved in future crises (e.g., caregivers, family members, community services). This can be done by giving a copy of your assessment, with clear recommendations, to the person.
accompanying the client to the ER and making arrangements for a copy to be provided to the caregiver who sees the client daily. For example, if the client is in a group home, a copy of your assessment recommendations (having obtained appropriate consent for release of information) should be sent to the client’s primary residential caregiver at the group home and to the group home manager. These recommendations should be accompanied with a specific request that they be passed along to family members, other caregivers, the client’s family doctor, psychiatrist and relevant community agencies. Where possible, you should try to make direct contact with the client’s community physician and provide direct feedback.

4.4 A final reminder

If this was your first experience of a client with intellectual disability in a crisis, and it felt uncomfortable, that’s OK. RELAX. No matter how disastrous a situation was, review it with colleagues, learn from it, and try to understand the personal and professional distress you may have experienced. Don’t react by denying further contact with this client, or by prejudging and rejecting other clients with intellectual disabilities. And don’t be afraid to seek expert help.

Debriefing and training is available through the Dual Diagnosis Resource Service at 416-535-8501 ext.7809. Such training can be most useful when your team has had a recent experience with a client so that questions can be focused on the realities of your circumstances and the issues you encountered while responding to the client.
## Summary

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References


Other resources


Health Evidence Bulletins — Wales. (See link to Learning Disabilities.) Available: hebw.uwcm.ac.uk


The University of Western Ontario. Developmental Disabilities Program. Available: www.psychiatry.med.uwo.ca/ddp
For information on other Centre for Addiction and Mental Health resource materials or to place an order, please contact:
Marketing and Sales Services
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33 Russell Street
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