This guide is intended for use by primary care providers and, where available, an interdisciplinary team (Part A), with input from patient’s caregivers or support persons (Part B). It aims to help identify the causes of behavioural problems, in order to plan for treatment and management, and prevent reoccurrence.

**PART A: PRIMARY CARE PROVIDER SECTION**

**Date** (dd/mm/yyyy):

**Presenting Behavioural Concerns:**

**Etiology** of developmental disability, if known:

- [ ] Autism spectrum disorder
- [ ] Hearing impairment
- [ ] Visual impairment
- [ ] Physical disability
- [ ] Other disability (specify): ________________
- [ ] Previous trauma
- [ ] Physical
- [ ] Emotional

**Family history of:**
- [ ] Medical disorders (specify)
- [ ] Psychiatric disorders (specify)

What is the patient’s most recent level of functioning on formal assessment? Year done: _______

- [ ] BORDERLINE
- [ ] MILD
- [ ] MODERATE
- [ ] SEVERE
- [ ] PROFOUND
- [ ] UNKNOWN

**DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS**

Patient brought to family physician with escalating behavioural concerns

- Individual communicating concerns verbally? YES
- Caregivers expressing concerns? YES
- Should there be concerns? (Is anyone at risk?) YES
- Medical condition? YES: Treat condition
- Problem with supports/Expectations? YES: Adjust supports or expectations
- Emotional issues? YES: Address issues
- Psychiatric disorder? YES: Treat disorder

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## PART A: PRIMARY CARE PROVIDER SECTION

**Name:**

**DOB:**

### 1. REVIEW OF POSSIBLE MEDICAL CONDITIONS  
[See also Preventive Care Checklist]

Many medical conditions present atypically in people with developmental disabilities. In some cases the only indicator of a medical problem may be a change in behaviour or daily functioning. Consider a complete review of systems, a physical exam, and necessary investigations until the cause of the behaviour change is identified.

Would you know if this patient was in pain?  

- [ ] No  
- [ ] Yes: If yes, how does this patient communicate pain?
  - [ ] Expresses verbally  
  - [ ] Points to place on body  
  - [ ] Expresses through non-specific behaviour disturbance (describe):

- [ ] Other (specify): ________________________________

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behaviour change?  

- [ ] No  
- [ ] Yes  
- [ ] Possibly: ________________________________

Assess/Rule out:

- [ ] Medical condition giving rise to physical discomfort (e.g., rash or itch)
- [ ] Medication side effect
- [ ] Change in medication
- [ ] Allergies
- [ ] Vision problem (e.g., cataracts)
- [ ] Hearing problem
- [ ] Dental problem
- [ ] Cardiovascular
- [ ] Respiratory
- [ ] Pneumonia
- [ ] GERD/Peptic ulcer disease/H.pylori infection
- [ ] Constipation, or other lower GI problems
- [ ] UTI
- [ ] Other:

**Comments:**

### 2. PROBLEMS WITH ENVIRONMENTAL SUPPORTS OR EXPECTATIONS

Review Caregiver Information  
Identify possible problems with supports or expectations

- [ ] Stress or change in the patient’s environment? (e.g., living situation, day program, family situation)
- [ ] Insufficient behavioural supports?
- [ ] Patient’s disabilities not adequately assessed or supported?  
  (e.g., sensory and communication supports for patients with autism)
- [ ] Insufficient staff resources?  
  (e.g., to implement treatment, recreational, vocational or leisure programs)
- [ ] Inconsistencies in supports and staff approaches?
- [ ] Insufficient training/education of direct care staff?
- [ ] Signs of possible caregiver burnout?  
  (e.g., negative attitudes towards person, impersonal care, difficult to engage with staff, no or poor follow through in treatment recommendations)

Do caregivers seem to have inappropriate expectations associated with:

- Recognizing or adjusting to identified patient needs  
- Over- or under-estimating patient’s abilities (boredom or under-stimulation)

**Comments:**
## PART A: PRIMARY CARE PROVIDER SECTION

<table>
<thead>
<tr>
<th>Name:</th>
<th>DOB:</th>
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### 3. REVIEW OF EMOTIONAL ISSUES

Review Caregiver Information  Identify possible emotional issues

**Summary and comments re emotional issues (e.g., related to change, stress, loss):**

### 4. REVIEW OF POSSIBLE PSYCHIATRIC DISORDERS

- History of diagnosed psychiatric disorder:  
  - [ ] No  
  - [ ] Yes – Diagnosis: ___________________________

- History of admission(s) to psychiatric facility:  
  - [ ] No  
  - [ ] Yes (specify): ___________________________

(See Appendix: Psychiatric Symptoms and Behaviours Screen)

**Summary and comments re symptoms and behaviours indicating possible psychiatric disorder:**

### SUMMARY OF FACTORS THAT MAY CONTRIBUTE TO BEHAVIOURAL ISSUES
PART A: PRIMARY CARE PROVIDER SECTION

 MANAGEMENT PLAN: Use the “Diagnostic Formulation of Behavioural Concerns” to assess and treat causative and contributing factors

1. Physical exam, medical investigations indicated
2. Risk assessment
3. Medication review
4. Referrals for functional assessments and specialized medical assessments as indicated
   • e.g., to psychologist, speech and language pathologist, occupational therapist for assessments and recommendations re adaptive functioning, communication, sensory needs or sensory diet
   • e.g., genetic assessment/reassessment, psychiatric consult
5. Assessment and treatment and referral as indicated for
   • Supports and expectations
   • Emotional issues
   • Psychiatric disorder
6. Review behavioural strategies currently being used, revise as needed
   • De-escalation strategies
     – Use of a quiet, safe place
     – Safety response plan
   • Supports
   • Use of “as needed” (PRN) medications
7. Identify and access local and regional interdisciplinary resources for care of patient
   • Case management resources
   • Behaviour therapist
   • Other
8. Focus on behaviours
   • Identify target symptoms and behaviours to monitor
   • Institute use of Antecedent-Behaviour-Consequence (ABC) Chart
9. Develop a proactive and written Crisis Prevention and Management Plan with caregivers and an interdisciplinary team
   • Applicable for all environments in which the behaviour could occur, e.g., home, day program or community
   • Caregivers to monitor for triggers of behaviour problems and use early intervention and de-escalation strategies
   • Periodic team collaboration to review issues, plan and revise, as needed
   • If hospital and/or Emergency Department (ED) involved, consider including ED staff in developing the Crisis Prevention and Management Plan
10. Regular and periodic medication review
    • Use Auditing Psychotropic Medication Therapy tool for review of psychotropic medications

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PART B: CAREGIVER SECTION
(Caregiver to fill out or provide information)

Name: 
DOB: 

What type of Developmental Disability does the patient have (i.e., what caused it?)
(e.g., Down syndrome, fragile X syndrome) ________________________________ □ Unsure/don’t know

What is the patient’s level of functioning?
☐ BORDERLINE  ☐ MILD  ☐ MODERATE  ☐ SEVERE  ☐ PROFOUND  ☐ UNKNOWN

BEHAVIOURAL PROBLEM

When did the behavioural problem start?
(dd/mm/yyyy) ________________________________

When was patient last “at his/her best”? (i.e., before these behaviour problems)
(dd/mm/yyyy) ________________________________

Description of current difficult behaviour(s):

Has this sort of behaviour happened before?

What, in the past, helped or did not help to manage the behaviour?
(include medications or trials of medications to manage behaviour[s])

What is being done now to try to help the patient and manage his/her behaviours? How is it working?

Risk?
☐ To self
☐ To others
☐ To environment
☐ Aggression to others
☐ Self-injurious behaviour

Severity of Damage or Injury
☐ mild (no damage)
☐ moderate (some)
☐ severe (extensive)

Frequency of Distressing (Challenging) Behaviour
☐ more than once daily
☐ daily
☐ weekly
☐ monthly

Please check (✓) if there has been any recent deterioration or change in:

☐ mood
☐ bowel/bladder continence
☐ appetite
☐ sleep
☐ social involvement
☐ communication
☐ interest (in leisure activities or work)
☐ seizure frequency
☐ self care (e.g., eating, toileting, dressing, hygiene)
☐ independence
☐ initiative
☐ cognition (e.g., thinking, memory)
☐ movement (standing, walking, coordination)
☐ need for change in supervision and/or placement

When did this change/deterioration start?

Caregiver comments:
PART B: CAREGIVER SECTION
(Caregiver to fill out or provide information)

Name: 
DOB: 

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS

Patient brought to family physician with escalating behavioural concerns

Individual communicating concerns verbally? YES

NO

Caregivers expressing concerns? YES

NO

Should there be concerns? (Is anyone at risk?) YES

NO

Medical condition? YES: Treat condition

NO

Problem with supports/Expectations? YES: Adjust supports or expectations

NO

Emotional issues? YES: Address issues

NO

Psychiatric disorder? YES: Treat disorder

NO

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1. POSSIBLE PHYSICAL HEALTH PROBLEMS OR PAIN

Are you or other caregivers aware of any physical health or medical problems that might be contributing to the patient’s behaviour problems? □ No □ Yes: If yes, please specify or describe:

Could pain, injury or discomfort be contributing to the behaviour change? □ No □ Yes □ Possibly Specify: ____________________________________________

Would you know if this patient was in pain? □ No □ Yes: How does this patient communicate pain?

□ Expresses verbally □ Points to place on body

□ Expresses through non-specific behaviour disturbance (describe): ____________________________________________

□ Other (specify): ____________________________________________

Are there any concerns about medications or possible medication side effects?

2.1: CHANGES IN ENVIRONMENT before problem behaviour(s) began

Have there been any recent changes or stressful circumstances in:

□ Caregivers? (family members, paid staff, volunteers)

□ Care provision? (e.g., new program or delivered differently, fewer staff to support)

□ Living environment? (e.g., co-residents)

□ School or day program?
## PART B: CAREGIVER SECTION

### 2.2: SUPPORT ISSUES

Are there any problems in this patient’s support system that may contribute to his/her basic needs not being met?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does this patient have a hearing or vision problem?</td>
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<td>Does this patient have a communication problem?</td>
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<tr>
<td>Does this patient have a problem with sensory triggers?</td>
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<tr>
<td>Does environment seem too physically demanding for this patient?</td>
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<tr>
<td>Does this patient have enough opportunities for appropriate physical activities?</td>
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<tr>
<td>Does this patient have mobility problems or physical restrictions?</td>
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</tbody>
</table>

If yes, do you think this patient’s environment is over-stimulating?   |     |
under-stimulating? or just right for this patient?                   |     |

Does environment seem too physically demanding for this patient?   | No | Yes |

Does this patient have enough opportunities for appropriate physical activities? | No | Yes |

Does this patient have mobility problems or physical restrictions?  | No | Yes: If yes, what is in place to help him/her? If yes, does he/she receive physiotherapy? |

Are there any supports or programs that might help this patient and which are not presently in place? | No | Yes: If yes, please describe: |

### 3: EMOTIONAL ISSUES

Please check (✓) if any of these factors may be affecting this patient:

- Any recent change in relationships with significant others (e.g., staff, family, friends, romantic partner)
- Additions (e.g., new roommate, birth of sibling)
- Losses (e.g., staff change, housemate change)
- Separations (e.g., decreased visits by volunteers, sibling moved out)
- Deaths (e.g., parent, housemate, caregiver)

<table>
<thead>
<tr>
<th>Issues of assault or abuse</th>
<th>Past</th>
<th>Ongoing</th>
<th>Date(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
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<tr>
<td>Sexual</td>
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<tr>
<td>Emotional</td>
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<tr>
<td>Exploitation</td>
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</tbody>
</table>

Comments:

- Teasing or bullying
- Anxiety about completing tasks
- Issues regarding sexuality and relationships
- Disappointment(s) (e.g., being surpassed by siblings; not being able to meet goals, such as driving or having a romantic relationship)
- Growing insight into disabilities and impact on own life (e.g., that he/she will never have children, sibling has boy/girlfriend)
- Life transitions (e.g., moving out of family home, leaving school, puberty)
- Other triggers (e.g., anniversaries, holidays, environmental, associated with past trauma)

Specify:

Caregiver Comments:
### PART B: CAREGIVER SECTION

<table>
<thead>
<tr>
<th>Name:</th>
<th>DOB:</th>
</tr>
</thead>
</table>

Has this patient ever been diagnosed with a psychiatric disorder?  
☐ Yes:  ☐ No  ☐ Unsure

Has this patient ever been hospitalized for a psychiatric reason?  
☐ Yes:  ☐ No  ☐ Unsure

#### CAREGIVER CONCERNS AND INFORMATION NEEDS

Do you, and other caregivers, have the information you need to help this patient, in terms of:

- The type of developmental disability the patient has and possible causes of it?  
  ☐ Yes  ☐ No  ☐ Unsure

- What the patient’s abilities, support needs, and potential are?  
  ☐ Yes  ☐ No  ☐ Unsure

- Possible physical health problems with this kind of disability?  
  ☐ Yes  ☐ No  ☐ Unsure

- Possible mental health problems and support needs with this kind of disability (e.g., anxiety more common with fragile X syndrome)?  
  ☐ Yes  ☐ No  ☐ Unsure

- How to help if the patient has behaviour problems/emotional issues?  
  ☐ Yes  ☐ No  ☐ Unsure

- Recent changes or deterioration in the patient’s abilities?  
  ☐ Yes  ☐ No  ☐ Unsure

Are there any issues of **caregiver stress** or potential burnout?  
☐ Yes  ☐ No  ☐ Unsure

**Caregiver comments:**

---

*Thank you for the information you have provided. It will be helpful in understanding this patient better and planning and providing health care for him or her.*
# PRIMARY CARE PROVIDERS AND CAREGIVERS: Psychiatric Symptoms and Behaviours Screen

Can be filled out by primary care provider, or by caregiver, and reviewed by primary care provider.

<table>
<thead>
<tr>
<th>Symptoms and behaviours</th>
<th>BASELINE 1</th>
<th>NEW</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anxiety-related</strong></td>
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<tr>
<td>Anxiety</td>
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<td>Panic</td>
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<td>Phobias</td>
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<td>Obsessive thoughts</td>
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<tr>
<td>Compulsive behaviours</td>
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<tr>
<td>Rituals/routines</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Mood-related</strong></td>
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<tr>
<td>Agitation</td>
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<tr>
<td>Irritability</td>
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<tr>
<td>Aggression</td>
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<tr>
<td>Self-harm behaviour</td>
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<tr>
<td>Depressed mood</td>
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<tr>
<td>Loss of interest</td>
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<tr>
<td>Unhappy/miserable</td>
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<tr>
<td>Under-activity</td>
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<tr>
<td>Sleep</td>
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<td>Eating pattern</td>
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<td>Appetite</td>
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<tr>
<td>Weight (provide details)</td>
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<tr>
<td>Elevated mood</td>
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<td>Intrusiveness</td>
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<td>Hypersexuality</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Psychotic-related</strong></td>
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<tr>
<td>Psychotic and psychotic-like symptoms (e.g., self talk, delusions, hallucinations)</td>
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<tr>
<td><strong>Movement-related</strong></td>
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<tr>
<td>Catatonia (‘stuck’)</td>
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<tr>
<td>Tics</td>
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<tr>
<td>Stereotypies (repetitive movements or utterances)</td>
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<tr>
<td><strong>ADHD-related or Mood Disorder</strong></td>
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<tr>
<td>Inattention</td>
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<tr>
<td>Hyperactivity</td>
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<tr>
<td>Impulsivity</td>
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<tr>
<td><strong>Dementia-related</strong></td>
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<td>Concentration</td>
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<td>Memory</td>
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<td>Other</td>
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<tr>
<td><strong>Other</strong></td>
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<tr>
<td>Alcohol misuse</td>
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<tr>
<td>Drug abuse</td>
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<tr>
<td>Sexual issues/problems</td>
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<tr>
<td>Psychosomatic complaints</td>
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</table>

1 Establish usual baseline i.e., behaviours and daily functioning before onset of concerns.

2 Use caution when interpreting psychotic-like symptoms and behaviours in patients with DD. These may be associated with anxiety (or other circumstances) rather than a psychotic disorder.