

A Guide to Understanding Behavioural Problems and Emotional Concerns

in Adults with Developmental Disabilities (DD) for Primary Care Providers and Caregivers

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:

Additional disabilities:

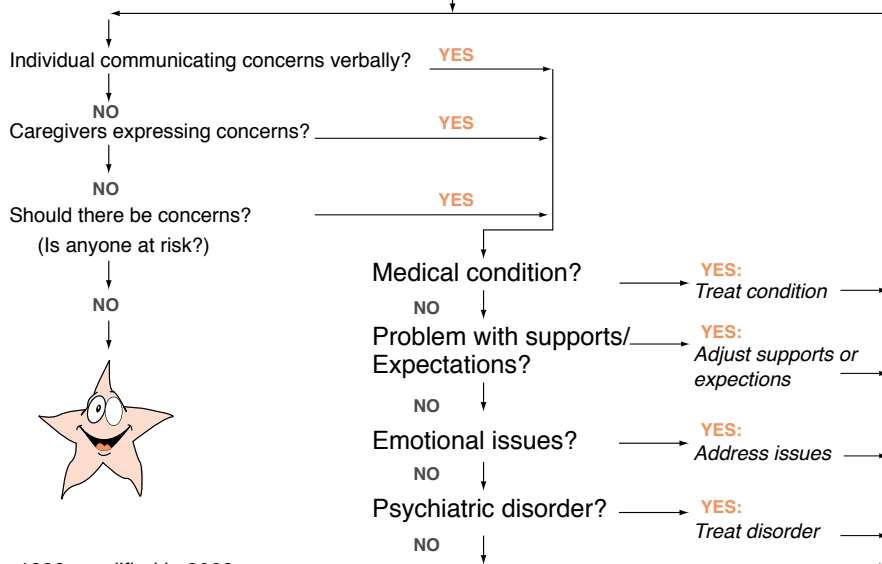
- Autism spectrum disorder
 Hearing impairment
 Visual impairment
 Physical disability
 Other disability (specify): _____
 Previous trauma
 Physical
 Emotional
 Family history of:
 Medical disorders (specify)
 Psychiatric disorders (specify)

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



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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: _____

- | | |
|--|---|
| <input type="checkbox"/> Medical condition giving rise to physical discomfort (e.g., rash or itch) | <input type="checkbox"/> Dysmenorrhea/Premenstrual syndrome |
| <input type="checkbox"/> Medication side effect | <input type="checkbox"/> Peri-menopausal/menopausal (may start earlier) |
| <input type="checkbox"/> Change in medication | <input type="checkbox"/> Musculoskeletal (arthritis, joints) |
| <input type="checkbox"/> Allergies | <input type="checkbox"/> Osteoporosis |
| <input type="checkbox"/> Vision problem (e.g., cataracts) | <input type="checkbox"/> Degenerative disc disease (DDD) |
| <input type="checkbox"/> Hearing problem | <input type="checkbox"/> Spasticity |
| <input type="checkbox"/> Dental problem | <input type="checkbox"/> Neurological (e.g., seizures, dementia) |
| <input type="checkbox"/> Cardiovascular | <input type="checkbox"/> Dermatological |
| <input type="checkbox"/> Respiratory | <input type="checkbox"/> Sensory discomfort (e.g., new clothes, shoes) |
| <input type="checkbox"/> Pneumonia | <input type="checkbox"/> Hypothyroidism |
| <input type="checkbox"/> GERD/Peptic ulcer disease/H.pylori infection | <input type="checkbox"/> Diabetes (I or II) |
| <input type="checkbox"/> Constipation, or other lower GI problems | <input type="checkbox"/> Sleep problems/sleep apnea |
| <input type="checkbox"/> UTI | |
| <input type="checkbox"/> 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 Yes No Unsure

Over- or under-estimating patient's abilities (boredom or under-stimulation) Yes No Unsure

Comments:

PART A: PRIMARY CARE PROVIDER SECTION

Name: _____

DOB: _____

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

Name:

DOB:

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

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:

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

When did this change/deterioration start?

Caregiver comments:

PART B: CAREGIVER SECTION

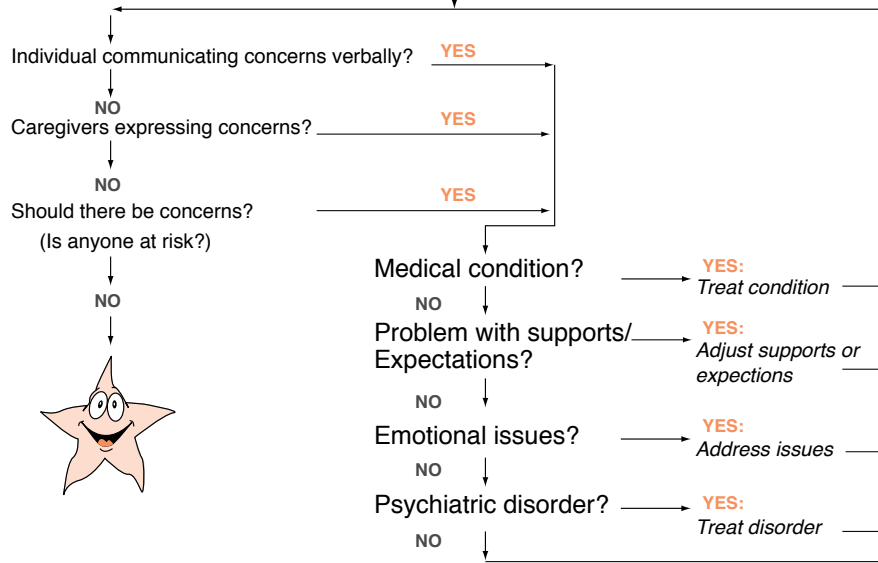
(Caregiver to fill out or provide information)

Name:

DOB:

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS

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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

Name:

DOB:

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?

Does this patient have a **hearing** or **vision problem**? No Yes: If yes, what is in place to help him/her?

Does this patient have a **communication problem**? No Yes: If yes, what is in place to help him/her?

Does this patient have a problem with **sensory triggers**? No Yes: If yes, what is in place to help him/her?
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:

Caregiver comments:

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)

Issues of assault or abuse

	Past	Ongoing	Date(s)
<input type="checkbox"/> Physical	<input type="checkbox"/>	<input type="checkbox"/>	_____
<input type="checkbox"/> Sexual	<input type="checkbox"/>	<input type="checkbox"/>	_____
<input type="checkbox"/> Emotional	<input type="checkbox"/>	<input type="checkbox"/>	_____
<input type="checkbox"/> Exploitation	<input type="checkbox"/>	<input type="checkbox"/>	_____

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)
- Being left out of an activity or group**
- Stress or upsetting event, at school or work**
- Inability to verbalize feelings**

Specify:

Caregiver Comments:

PART B: CAREGIVER SECTION

Name:

DOB:

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

Yes: _____

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

Yes: _____

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:

Caregiver's additional general comments or concerns:

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		Name:	
		DOB:	
Can be filled out by primary care provider , or by caregiver , and reviewed by primary care provider.			
Symptoms and behaviours	BASELINE ¹ Check if usually present	NEW Check if recent onset	COMMENTS If new onset or increased
Anxiety-related			
Anxiety			
Panic			
Phobias			
Obsessive thoughts			
Compulsive behaviours			
Rituals/routines			
Other			
Mood-related			
Agitation			
Irritability			
Aggression			
Self-harm behaviour			
Depressed mood			
Loss of interest			
Unhappy/miserable			
Under-activity			
Sleep			
Eating pattern			
Appetite			
Weight (provide details)			
Elevated mood			
Intrusiveness			
Hypersexuality			
Other			
Psychotic-related ²			
Psychotic and psychotic-like symptoms (e.g., self talk, delusions, hallucinations)			
Movement-related			
Catatonia ('stuck')			
Tics			
Stereotypies (repetitive movements or utterances)			
ADHD-related or Mood Disorder			
Inattention			
Hyperactivity			
Impulsivity			
Dementia-related			
Concentration			
Memory			
Other			
Other			
Alcohol misuse			
Drug abuse			
Sexual issues/problems			
Psychosomatic complaints			

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.