A Guide to Understanding Behavioural Problems and Emotional Concerns

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

Name: ______________________________ Gender: ____
(last, first)

Address: ______________________________

Tel. No: ______________________________

DOB (dd/mm/yyyy): ______________________________

Health Card Number: ______________________________

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

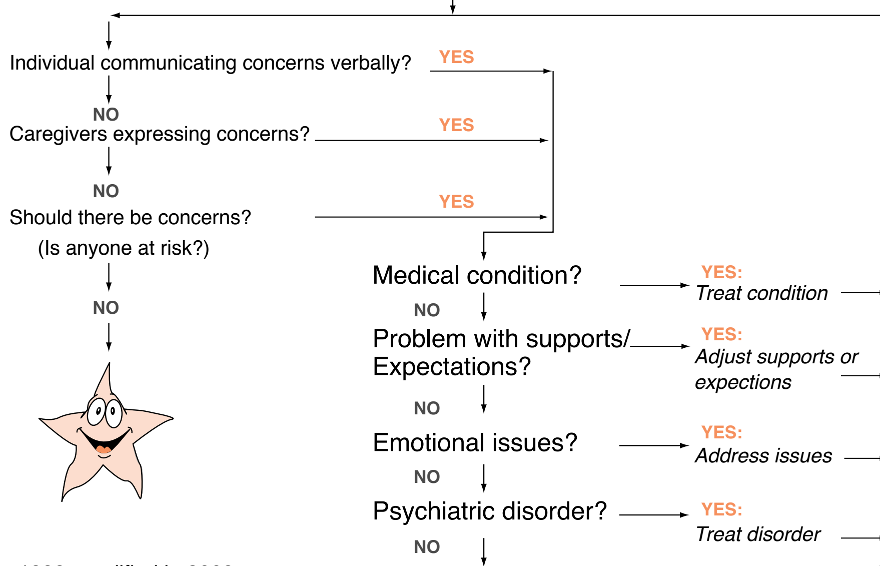
☐ Other disability (specify): ____________________ ☐ Previous trauma ☐ Physical ☐ Emotional

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



© Bradley & Summers 1999; modified in 2009

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
☐ Dysmenorrhea/Premenstrual syndrome
☐ Peri-menopausal/menopausal (may start earlier)
☐ Musculoskeletal (arthritis, joints)
☐ Osteoporosis
☐ Degenerative disc disease (DDD)
☐ Spasticity
☐ Neurological (e.g., seizures, dementia)
☐ Dermatological
☐ Sensory discomfort (e.g., new clothes, shoes)
☐ Hypothyroidism
☐ Diabetes (I or II)
☐ Sleep problems/sleep apnea

☐ 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:

© 2011 Surrey Place Centre

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

© 2011 Surrey Place Centre

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

 © 2011 Surrey Place Centre

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?		Severity of Damage or Injury	Frequency of Distressing (Challenging) Behaviour
☐ To self ☐ To others ☐ To environment	☐ Aggression to others ☐ Self-injurious behaviour	☐ mild (no damage) ☐ moderate (some) ☐ severe (extensive)	☐ 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

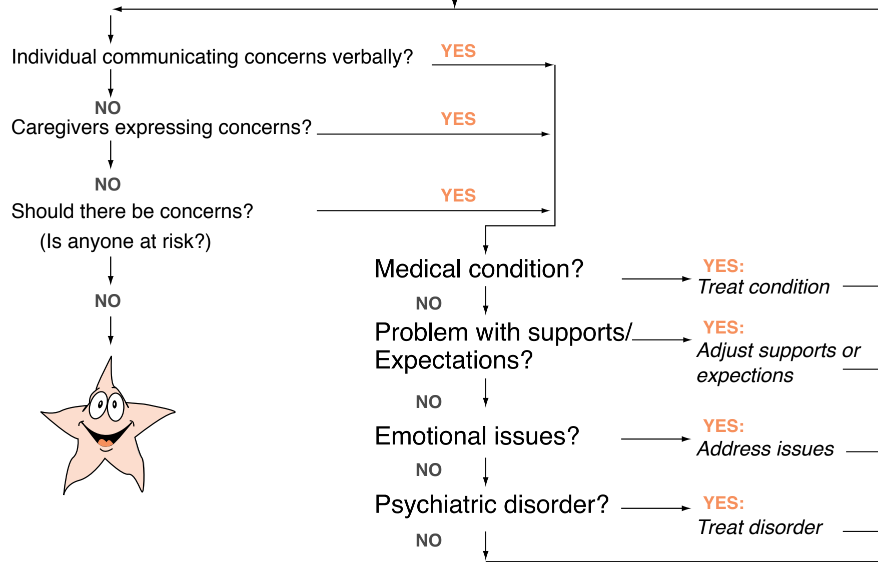
When did this change/deterioration start?

Caregiver comments:

© 2011 Surrey Place Centre

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

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS



© Bradley & Summers 1999; modified in 2009

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?**

 © 2011 Surrey Place Centre

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)
☐ Physical	☐	☐	____________
☐ Sexual	☐	☐	____________
☐ Emotional	☐	☐	____________
☐ Exploitation	☐	☐	____________

Comments:

- ☐ **Teasing or bullying**
- ☐ **Anxiety about completing tasks**
- ☐ **Issues regarding sexuality and relationships**
- ☐ **Being left out of an activity or group**
- ☐ **Stress or upsetting event, at school or work**
- ☐ **Inability to verbalize feelings**
- ☐ **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:

© 2011 Surrey Place Centre

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.*

© 2011 Surrey Place Centre

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.

© 2011 Surrey Place Centre