TODAY'S VISIT

Main Reason for Today's Visit to the Physician or Nurse
(To be filled out by the Patient with DD and Caregiver)

- Please bring an updated form for each visit to the physician/nurse.
- Bring an updated medication list, or all medications being taken.
- Bring any monitoring forms being used (i.e., sleep or behaviour charts).
- Keep a copy of this completed form for the patient's home medical files.

Up-to-date Medication List attached? ☐

Name: _____ Gender: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit: _____

Patient / Caregiver (see back of page)

What is the main health problem the patient with DD or caregivers are concerned about?

When did it start? List any new symptoms. List possible contributing factors.

Circle or list other needs – e.g., prescription renewals, test results, forms to be filled out, appointment for annual exam

Any Recent Changes or Stressors? ☐ **No** ☐ **Yes:** _____
(e.g., staff changes, family illness or stress, changes in living or social environment)

Any recent visit to the dentist or other doctor? ☐ **No** ☐ **Yes:** _____

Any recent medication changes or additions? ☐ **No** ☐ **Yes:** _____
(include antibiotics, creams or herbal medicines)

Caregiver Needs – Write down or tell doctor or nurse whether there are issues regarding caregiver fatigue or burnout

Name/Position:	**Contact #:**	**Signature:**

PHYSICIAN / NURSE TO COMPLETE, KEEP COPY FOR CHART, AND GIVE COPY TO THE PATIENT / CAREGIVER

Physician / Nurses

Assessment:	
Treatment Plan including Medication Changes:	
Advice to Patient and Caregivers:	

Next Planned Visit / Follow-Up: _____ **MD / RN Signature:** _____

Recent Changes? If yes, check and briefly describe. Complete appropriate sections of monitoring chart below

- ☐ **Activity level**
- ☐ **Sleeping habits**
- ☐ **Eating patterns/Weight change**
- ☐ **Bowel routine**
- ☐ **Mobility**
- ☐ **Pain or distress**
- ☐ **Swallowing**
- ☐ **Mood or behaviour**
- ☐ **Other:** _____

MONITORING OF DAILY FUNCTIONS DURING THE PAST WEEK

	MON.	TUES.	WED.	THURS.	FRI.	SAT.	SUN.
ACTIVITY LEVEL (N, ☒ or ☒)							
SLEEP Pattern and Hours required (daytime and night)							
EATING/ WEIGHT (N, ☒ or ☒) Include total # of meals and # completed/day							
BOWEL ROUTINE (N, ☒, ☒, C)							
MOOD/ BEHAVIOUR (N, ☒ or ☒) Describe if changed (e.g., agitated, withdrawn)							

Fill in chart using: **N = Normal** or usual for that person; ☒ = **Decrease** in amount, level or function; ☒ = **Increase** in amount, level or function
C = Constipation – a stool is passed less often than every two days or stools are hard and/or difficult or painful to pass, even if the person has stools many times per week.

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

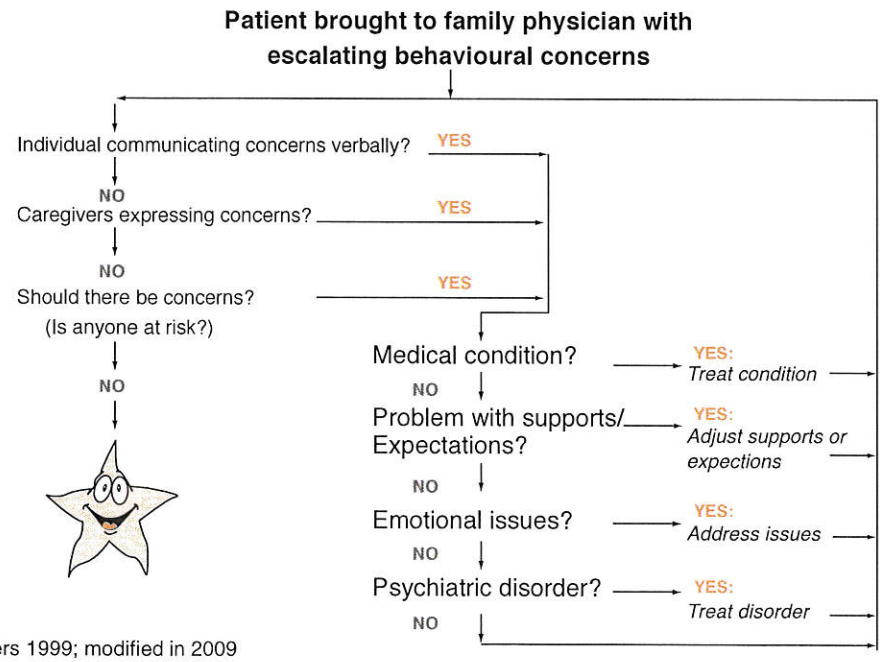
☐ Other disability (specify): _____ ☐ Previous trauma ☐ Physical ☐ Emotional

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



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:

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:

- ☐ 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?

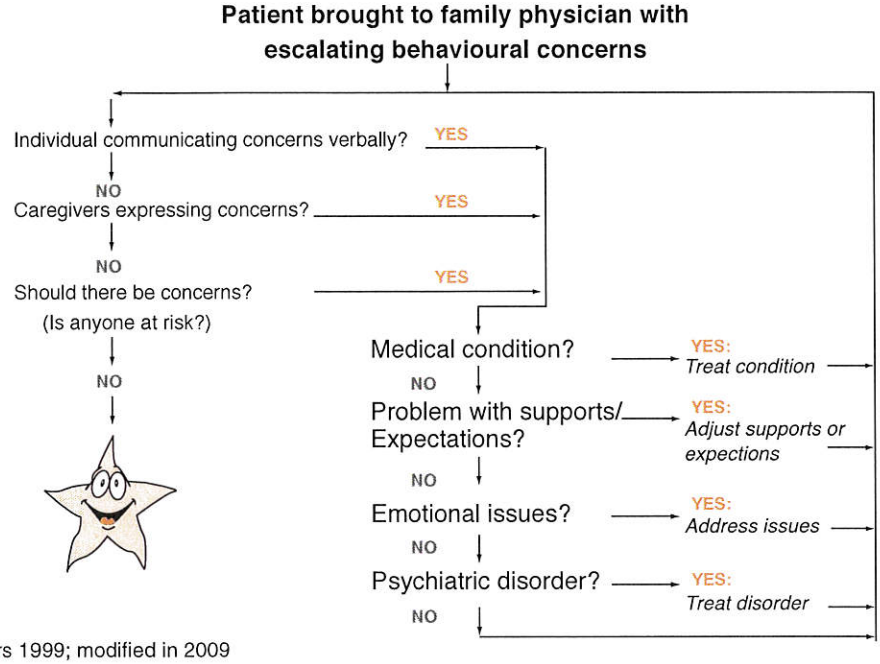
Caregiver comments:

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

Name:

DOB:

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS



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)
☐ 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:

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.

ABC (Antecedent-Behaviour-Consequence) Chart

To record baseline information for incongruent, challenging or problematic behaviours*

Name:

DOB:

Occasion Date Time Observer	**Pre-existing conditions** Factors that increase vulnerability or sensitivity to triggers	**Antecedent** What happened just before the behaviour occurred and might have triggered it? Include SETTING & ACTIVITY	**Behaviour** Describe the behaviour as accurately and specifically as possible. Include frequency, duration, and intensity on a scale of 1 to 5 (5 is most severe).	**Consequence** Things that happened immediately after the behaviour occurs,and make it more or less likely to happen again
Example				
Date Feb 6/10 **Time** 6:30-7:10 pm **Observer** Rene – primary staff member	John's mother was in hospital with broken hip, and could not visit. John had a toothache. John's usual primary staff member was on holidays.	John was eating supper in kitchen when another resident bumped into him when passing food.	John started to yell and threw his plate across the table. He ran out of room, screamed for 10 minutes and threw cushions around living room. The intensity was 4/5.	Staff tried to direct John to his room for a time-out but he became more agitated. They also tried to distract him with ice cream but were unsuccessful. They directed other residents to leave the room. John began to hit staff when they approached him. Staff observed him from a distance, gave him time and reduced stimuli, and he calmed down in about 30 min.
Date **Time** **Observer**				
Date **Time** **Observer**				
Date **Time** **Observer**				

*Adapted from **www.peatni.org/directory/resources/index.asp** with input from **Caroll Drummond**, Behaviour Therapist, Surrey Place Centre

Community Resources in Ontario
for Adults with Developmental Disabilities (DD), including Mental Health Resources

Ministry of Community and Social Services (MCSS) – Developmental Services Branch:
Developmental Services fall under the umbrella of MCSS

- Ontario is divided into nine regions with a Regional Director for each regional office
- Services and supports for adults with DD, 19 years and older, include:
  – transition for young adults leaving school
  – community, financial, employment, residential and family supports
  – case management

If the adult with DD does not have a case manager and appropriate services, contact the Regional MCSS Office at 1-866-340-8881(toll-free main number) or go to **www.mcss.gov.on.ca/en/mcss/regionalmap/regional.aspx**.

Starting July 1, 2011, under the new umbrella of "Developmental Services Ontario", a single agency will serve as the regional contact and service coordination point in each of the nine provincial regions. Go to **www.mcss.gov.on.ca/en/mcss/programs/developmental/improving/new_application.aspx**.

Community Networks of Specialized Care (CNSC) www.community-networks.ca

- Coordinate specialized services for adults with DD with behavioural or mental health issues (dual diagnosis).
- Each regional Network has a CNSC Coordinator who works with local community agencies and mental health service providers to coordinate access to appropriate services.
- They can be a very helpful starting point for accessing services for patients with DD and complex behavioural/mental health issues.

ConnexOntario – Mental Health Service Information Ontario (MHSIO) www.mhsio.on.ca

- This province-wide information and referral service provides Ontarians with round-the-clock access to information about mental health services and supports.
- Funded by the Ontario Ministry of Health and Long-Term Care (MOHLTC).
- Designed to link callers with suitable options tailored to their individual needs.
- MHSIO operates a confidential and anonymous Information Line (1-866-531-2600) which is available 24 hours a day, seven days a week.

Respite Services for Families in Ontario www.respiteservices.com
Lists respite programs and services for children and adults in Ontario, by location.

CAMH (Centre For Addiction And Mental Health) http://knowledgex.camh.net
Effective July 2011, a new toolkit for primary care providers will be posted on the CAMH Knowledge Exchange website. It was developed by CAMH, Surrey Place Centre and the CNSCs, with input from primary care providers. This toolkit will list the resources needed to help primary care patients with DD and their caregivers, and will include resources for situations of behaviour concerns or crises.

Guidance About Emergencies for Caregivers

ATTEND TO SAFETY ISSUES How can the person in crisis, staff, other residents and the environment be kept safe?	• Use existing successful strategies to manage escalating behaviours • Can the person with developmental disabilities (DD) be safely contained in a quiet, safe place? • What changes can be made in his/her environment to make him/her, other people, and the environment safe? • Is there "as needed" or PRN medication that generally helps the person, and that can safely be given? • Physical restraint is against policy, and not a legal option in group homes
KEEP IN MIND	• Person with DD and caregiver preferences in decision-making process • Attend to uniqueness of the person with DD
POINT OUT	• Any possible medical symptoms that family/staff may have noticed, for Emergency Medical Services (EMS) and Emergency Department (ED) staff • How the person typically communicates pain and distress

IF SENDING THE PERSON WITH DD TO EMERGENCY DEPARTMENT OR CALLING 911:

- Complete and send Essential Information for Emergency Department (ED)
- Attach list of all **current medications** from Medication Administration Record (MAR) or pharmacy list and bring medications
- **If PRN medication** is already part or the behavioural management, consider whether an **additional PRN** would assist the person with DD prior to going to the ED
- Consider bringing photos or video showing how this person acts when calm and not calm

WHEN CONTACTING 911

- Explain that the person has a developmental disability
- Alert EMS staff to any special needs, for example:
  - Best way to communicate
  - Importance of caregiver presence to help the person feel safe and comfortable
  - Sensitivity to sensory issues (e.g., noise, lights, textures, personal space)
  - Sensitivity to restraints
  - Reaction of the person with DD to uniformed police, and other people in uniforms or strangers

PATIENT COMFORT PACKAGE FOR ED/HOSPITAL VISITS

Encourage patient/caregivers to bring:

- Comforters (e.g., security blanket, stuffed animal, favourite book, photos)
- Favourite food/drink and snacks (the wait can be long and food may be limited)
- Communication strategies that work (communication aids)
- Someone who knows the person well and knows how hospitals work
- Ways (e.g., photos - video/digital) to illustrate what the person with DD is usually like
- Explanation about how hospitals work (social story appropriate for the person's developmental level)

Bring all medications for the next 12 hours as ED will not dispense regular medications.

Developed by: ***Yona Lunsky**, Psychologist, Centre for Addiction and Mental Health*

Medication Questions Form

Questions	
Name of medication:	
Is it FDA approved for use with this age group?	
Write down reason it is being prescribed	
Why has the doctor picked this specific medication?	
What do we expect to change as an indication that it is helping?	
What are the side effects to watch out for? (can also ask pharmacist for info printout)	
How long will it take to see changes?	
How will we evaluate if it is helping?	
Other notes and comments:	

TODAY'S VISIT

Main Reason for Today's Visit to the Physician or Nurse
(To be filled out by the Patient with DD and Caregiver)

- Please bring an updated form for each visit to the physician/nurse.
- Bring an updated medication list, or all medications being taken.
- Bring any monitoring forms being used (i.e., sleep or behaviour charts).
- Keep a copy of this completed form for the patient's home medical files.

Up-to-date Medication List attached? ☐

Name: _____ Gender: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit: _____

Patient / Caregiver (see back of page)

What is the main health problem the patient with DD or caregivers are concerned about?

When did it start? List any new symptoms. List possible contributing factors.

Circle or list other needs – e.g., prescription renewals, test results, forms to be filled out, appointment for annual exam

Any Recent Changes or Stressors? ☐ **No** ☐ **Yes:** _____
(e.g., staff changes, family illness or stress, changes in living or social environment)

Any recent visit to the dentist or other doctor? ☐ **No** ☐ **Yes:** _____

Any recent medication changes or additions? ☐ **No** ☐ **Yes:** _____
(include antibiotics, creams or herbal medicines)

Caregiver Needs – Write down or tell doctor or nurse whether there are issues regarding caregiver fatigue or burnout

Name/Position:	**Contact #:**	**Signature:**

PHYSICIAN / NURSE TO COMPLETE, KEEP COPY FOR CHART, AND GIVE COPY TO THE PATIENT / CAREGIVER

Physician / Nurses

Assessment:	
Treatment Plan including Medication Changes:	
Advice to Patient and Caregivers:	

Next Planned Visit / Follow-Up: _____ **MD / RN Signature:** _____

Recent Changes? If yes, check and briefly describe. Complete appropriate sections of monitoring chart below

- ☐ **Activity level**
- ☐ **Sleeping habits**
- ☐ **Eating patterns/Weight change**
- ☐ **Bowel routine**
- ☐ **Mobility**
- ☐ **Pain or distress**
- ☐ **Swallowing**
- ☐ **Mood or behaviour**
- ☐ **Other:** _____

MONITORING OF DAILY FUNCTIONS DURING THE PAST WEEK

	MON.	TUES.	WED.	THURS.	FRI.	SAT.	SUN.
ACTIVITY LEVEL (N, ☒ or ☒)							
SLEEP Pattern and Hours required (daytime and night)							
EATING/ WEIGHT (N, ☒ or ☒) Include total # of meals and # completed/day							
BOWEL ROUTINE (N, ☒, ☒, C)							
MOOD/ BEHAVIOUR (N, ☒ or ☒) Describe if changed (e.g., agitated, withdrawn)							

Fill in chart using: **N = Normal** or usual for that person; ☒ = **Decrease** in amount, level or function; ☒ = **Increase** in amount, level or function
C = Constipation – a stool is passed less often than every two days or stools are hard and/or difficult or painful to pass, even if the person has stools many times per week.

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

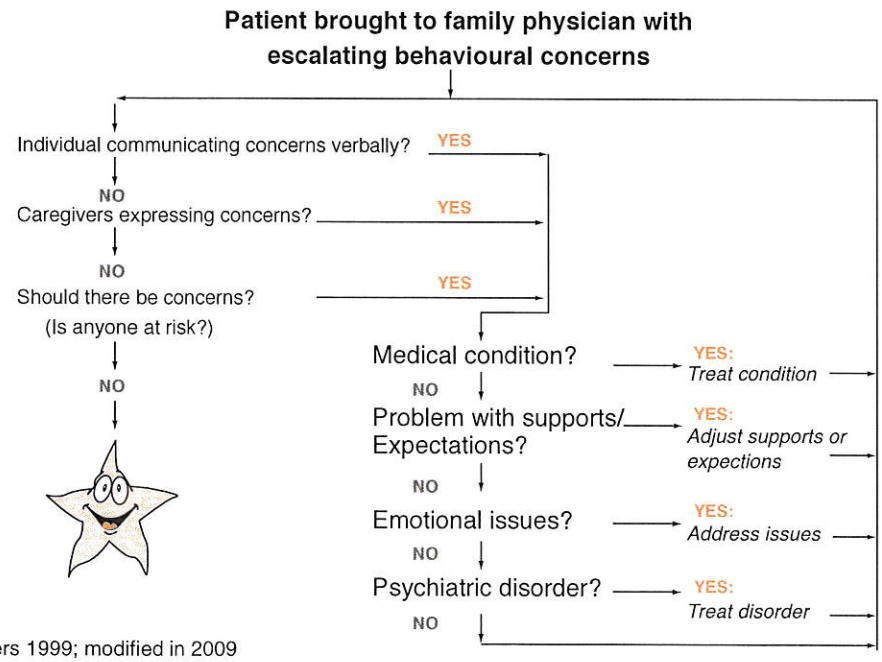
☐ Other disability (specify): _____ ☐ Previous trauma ☐ Physical ☐ Emotional

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



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:

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:

- ☐ 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?

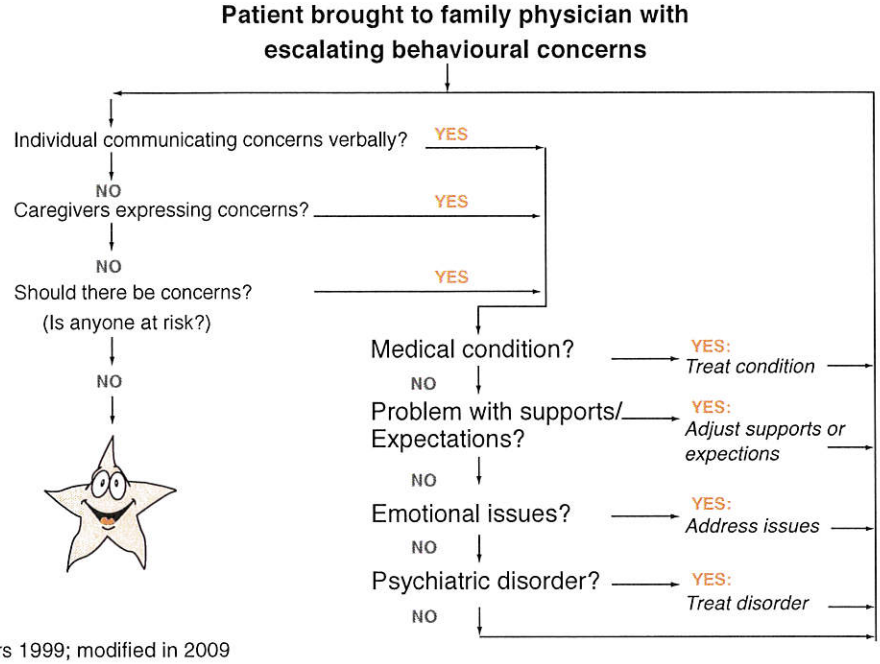
Caregiver comments:

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

Name:

DOB:

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS



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)
☐ 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:

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.

ABC (Antecedent-Behaviour-Consequence) Chart

To record baseline information for incongruent, challenging or problematic behaviours*

Name:

DOB:

Occasion Date Time Observer	**Pre-existing conditions** Factors that increase vulnerability or sensitivity to triggers	**Antecedent** What happened just before the behaviour occurred and might have triggered it? Include SETTING & ACTIVITY	**Behaviour** Describe the behaviour as accurately and specifically as possible. Include frequency, duration, and intensity on a scale of 1 to 5 (5 is most severe).	**Consequence** Things that happened immediately after the behaviour occurs,and make it more or less likely to happen again
Example				
Date Feb 6/10 **Time** 6:30-7:10 pm **Observer** Rene – primary staff member	John's mother was in hospital with broken hip, and could not visit. John had a toothache. John's usual primary staff member was on holidays.	John was eating supper in kitchen when another resident bumped into him when passing food.	John started to yell and threw his plate across the table. He ran out of room, screamed for 10 minutes and threw cushions around living room. The intensity was 4/5.	Staff tried to direct John to his room for a time-out but he became more agitated. They also tried to distract him with ice cream but were unsuccessful. They directed other residents to leave the room. John began to hit staff when they approached him. Staff observed him from a distance, gave him time and reduced stimuli, and he calmed down in about 30 min.
Date **Time** **Observer**				
Date **Time** **Observer**				
Date **Time** **Observer**				

*Adapted from **www.peatni.org/directory/resources/index.asp** with input from **Caroll Drummond**, Behaviour Therapist, Surrey Place Centre

Community Resources in Ontario
for Adults with Developmental Disabilities (DD), including Mental Health Resources

Ministry of Community and Social Services (MCSS) – Developmental Services Branch:
Developmental Services fall under the umbrella of MCSS

- Ontario is divided into nine regions with a Regional Director for each regional office
- Services and supports for adults with DD, 19 years and older, include:
  – transition for young adults leaving school
  – community, financial, employment, residential and family supports
  – case management

If the adult with DD does not have a case manager and appropriate services, contact the Regional MCSS Office at 1-866-340-8881(toll-free main number) or go to **www.mcss.gov.on.ca/en/mcss/regionalmap/regional.aspx**.

Starting July 1, 2011, under the new umbrella of "Developmental Services Ontario", a single agency will serve as the regional contact and service coordination point in each of the nine provincial regions. Go to **www.mcss.gov.on.ca/en/mcss/programs/developmental/improving/new_application.aspx**.

Community Networks of Specialized Care (CNSC) www.community-networks.ca

- Coordinate specialized services for adults with DD with behavioural or mental health issues (dual diagnosis).
- Each regional Network has a CNSC Coordinator who works with local community agencies and mental health service providers to coordinate access to appropriate services.
- They can be a very helpful starting point for accessing services for patients with DD and complex behavioural/mental health issues.

ConnexOntario – Mental Health Service Information Ontario (MHSIO) www.mhsio.on.ca

- This province-wide information and referral service provides Ontarians with round-the-clock access to information about mental health services and supports.
- Funded by the Ontario Ministry of Health and Long-Term Care (MOHLTC).
- Designed to link callers with suitable options tailored to their individual needs.
- MHSIO operates a confidential and anonymous Information Line (1-866-531-2600) which is available 24 hours a day, seven days a week.

Respite Services for Families in Ontario www.respiteservices.com
Lists respite programs and services for children and adults in Ontario, by location.

CAMH (Centre For Addiction And Mental Health) http://knowledgex.camh.net
Effective July 2011, a new toolkit for primary care providers will be posted on the CAMH Knowledge Exchange website. It was developed by CAMH, Surrey Place Centre and the CNSCs, with input from primary care providers. This toolkit will list the resources needed to help primary care patients with DD and their caregivers, and will include resources for situations of behaviour concerns or crises.

Guidance About Emergencies for Caregivers

ATTEND TO SAFETY ISSUES How can the person in crisis, staff, other residents and the environment be kept safe?	• Use existing successful strategies to manage escalating behaviours • Can the person with developmental disabilities (DD) be safely contained in a quiet, safe place? • What changes can be made in his/her environment to make him/her, other people, and the environment safe? • Is there "as needed" or PRN medication that generally helps the person, and that can safely be given? • Physical restraint is against policy, and not a legal option in group homes
KEEP IN MIND	• Person with DD and caregiver preferences in decision-making process • Attend to uniqueness of the person with DD
POINT OUT	• Any possible medical symptoms that family/staff may have noticed, for Emergency Medical Services (EMS) and Emergency Department (ED) staff • How the person typically communicates pain and distress

IF SENDING THE PERSON WITH DD TO EMERGENCY DEPARTMENT OR CALLING 911:

- Complete and send Essential Information for Emergency Department (ED)
- Attach list of all **current medications** from Medication Administration Record (MAR) or pharmacy list and bring medications
- **If PRN medication** is already part or the behavioural management, consider whether an **additional PRN** would assist the person with DD prior to going to the ED
- Consider bringing photos or video showing how this person acts when calm and not calm

WHEN CONTACTING 911

- Explain that the person has a developmental disability
- Alert EMS staff to any special needs, for example:
  - Best way to communicate
  - Importance of caregiver presence to help the person feel safe and comfortable
  - Sensitivity to sensory issues (e.g., noise, lights, textures, personal space)
  - Sensitivity to restraints
  - Reaction of the person with DD to uniformed police, and other people in uniforms or strangers

PATIENT COMFORT PACKAGE FOR ED/HOSPITAL VISITS

Encourage patient/caregivers to bring:

- Comforters (e.g., security blanket, stuffed animal, favourite book, photos)
- Favourite food/drink and snacks (the wait can be long and food may be limited)
- Communication strategies that work (communication aids)
- Someone who knows the person well and knows how hospitals work
- Ways (e.g., photos - video/digital) to illustrate what the person with DD is usually like
- Explanation about how hospitals work (social story appropriate for the person's developmental level)

Bring all medications for the next 12 hours as ED will not dispense regular medications.

Developed by: ***Yona Lunsky**, Psychologist, Centre for Addiction and Mental Health*

Medication Questions Form

Questions	
Name of medication:	
Is it FDA approved for use with this age group?	
Write down reason it is being prescribed	
Why has the doctor picked this specific medication?	
What do we expect to change as an indication that it is helping?	
What are the side effects to watch out for? (can also ask pharmacist for info printout)	
How long will it take to see changes?	
How will we evaluate if it is helping?	
Other notes and comments:	