COMMUNICATING EFFECTIVELY

Some people with intellectual or developmental disabilities (IDD) have communication difficulties. People with intellectual disabilities or those whose disabilities directly affect speech, hearing, or sight are more likely to have communication difficulties. Unless a communication barrier is obvious, it is best not to assume one exists unless the patient, a family member, or other caregiver tells you about the barrier. Even when a communication difficulty exists, the exact barrier and the best way to address it often varies.

When a person with a disability does have difficulty with communication, it may be helpful to keep the following in mind:

- Allow additional time to exchange information.
- An assessment of language skills helps to choose the level of language you use. Talking with someone with a mild communication difficulty is very different than talking with a person with a moderate or severe communication difficulty.
- Many people have stronger receptive (understanding) communication skills than expressive skills.
- Conversely, a person’s expressive speech may sometimes give an impression of better comprehension than is actually the case, so check the patient’s understanding.
- Some people may be delayed in responding to questions; so much so that answers may seem to “come out of nowhere.”
- Some people with severe disabilities may also have difficulty giving you an accurate picture of their feelings and symptoms because of limitations in interpreting internal cues (e.g., need to urinate, anxiety). Involving caregivers who know the patient well
may help you to better understand his/her experiences. However, as much as possible, continue to focus your communication efforts on the patient.

- If you are in a busy area with many distractions, consider moving to a quieter location.

### GOAL

#### ESTABLISHING RAPPORT

- Speak directly with the patient
- Avoid talking to an adult as if he/she were a child

### SUGGESTED COMMUNICATION TIPS

- Consider not wearing the white coat.
- Speak directly to the patient, not to his/her caregiver(s).
- Ask the patient: “Do you want your support worker/caregiver to stay here for this visit?”
- Ask simple introductory questions (e.g., name, reason for visit).
- Explain the process and purpose of the visit in simple terms.
- Gain the patient’s attention and eye contact, if possible, by using his/her name or by touching his/her arm prior to speaking.
- Determine how the patient communicates: “How do you say Yes? No?” “Do you use a device? Can you show me how to use this book/machine?”
- If the patient uses a communication technique or device, involve a caregiver who is familiar with it.
- Show warmth and a positive regard.
- Encourage the use of “comforters” (e.g., favorite item the patient likes to carry, or a preference for standing and pacing rather than sitting).
- For individuals with autism and related disorders, respect the preference to avoid eye contact.
- Use positive comments and positive reinforcement.
- Focus on the patient’s abilities rather than disabilities.

### CHOOSING APPROPRIATE LANGUAGE

- Use concrete language
- Avoid shouting
- Use plain language. Avoid jargon.
- Use short, simple sentences.
- Use concrete as opposed to abstract language, for example: “Show me”; “Tell me”; “Do this” with gesture; “Come with me”; “I’m going to...”
- Say “Put your coat on” instead of “get ready.”
○ Say “Are you upset? Are you sad? Are you happy?” instead of “What are you feeling?”
○ To make the concept of time more concrete, use examples from daily and familiar routines (e.g., breakfast-time, lunchtime, bedtime).

LISTENING

○ Listen to what the patient says
○ Allow enough time

○ Let the patient know when you do and do not understand.
○ Be sensitive to tone of voice and nonverbal cues.
○ Differences in muscle tone for some individuals may complicate reading their facial expressions or body language. Check/validate your perceptions.
○ Be aware that the visit will likely take more time than usual.
○ Several consultations may be required to complete a full assessment.

EXPLAINING CLEARLY

○ Explain what will happen before you begin
○ Tell and show what you are going to do and why

○ Speak slowly. Do not shout.
○ Pause frequently, so as not to overload the patient with words.
○ Give the patient enough time to understand what you have said and to respond.
○ Rephrase and repeat questions, if necessary, or write them out, if the patient is able to read.
○ Checking for understanding is essential. For patients who can speak in sentences, ask questions such as: “Can you tell me what I just said?” “Can you tell me what I am going to do and why?”

COMMUNICATING WITHOUT WORDS

○ Use visual aids
○ Act or demonstrate

○ People with limited language ability and understanding rely on familiar routines and environmental cues to understand or anticipate what will happen next.
○ Use simple diagrams and gestures.
○ Use pictures when communicating; find signs in the patient’s communication book or point to familiar objects (e.g., “It looks like...”)
○ Some people with IDD may express themselves only in writing.
○ When possible and safe, allow the patient to handle and explore equipment.
Point to body parts and act out actions or procedures (e.g., checking ears).

LEGAL OBIGATIONS TO PATIENTS WITH DISABILITIES

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504) require doctors and other health care providers to ensure effective communication with patients with disabilities. This obligation includes providing auxiliary aids and services to assist with communication.

These federal laws require health care providers to provide and pay for auxiliary aids/services necessary for effective communication. These laws prohibit health care providers from passing costs of auxiliary aids/services to their patients.

Whether a patient needs an auxiliary aid/service and, if so, what aid/service will vary from individual to individual. Examples of auxiliary aids/services include but are not limited to the following:

- Sign language interpreters
- Braille materials
- Simplified language documents
- Computer Assisted Real Time text (CART)
- Large print documents

Keep in mind that if a patient with a disability is accompanied by a companion who has a disability that affects communication, the ADA and Section 504 require medical providers to ensure effective communication with that companion, if he or she is an individual who is involved in the patient’s care.

Remember that these tips are general guidance and will need to be adapted depending on the abilities and needs of your individual patient. Your goal should be to treat people with disabilities just as you would other patients while respecting any disability-related needs those patients may have.

REFERENCES

2. Chew KL, Iacono T, Tracy J. Overcoming communication barriers – working with


6. Citation for ADA is 42 U.S.C. §§ 12101 et seq.

7. Citation for Section 504 is 29 U.S.C. § 794

Original tool: ©2011 Surrey Place Centre. Developed by Sullivan, W & Developmental Disabilities Primary Care Initiative Co-editors. Funded by the Ontario Ministry of Community and Social Services and Ontario Ministry of Health and Long-Term Care, Surrey Place Centre and the Surrey Place Centre Charitable Foundation.

Modified with permission of Surrey Place Centre. This tool was reviewed and adapted for U.S. use by physicians on the Toolkit’s Advisory Committee; for list, view here.

Additional reviewers were Lynne F. Harmon, MA, CCC-SLP, President/Co-Director, Parent-Child Services, Knoxville, TN, and Martha M. Lafferty, JD, Managing Attorney, Disability Law & Advocacy Center of Tennessee, Nashville, TN.
INFORMED CONSENT IN ADULTS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

Informed consent requires a physician or other health care provider to furnish a patient with information sufficient to allow the patient to understand and give approval for a proposed medical treatment or the performance of a particular medical procedure. Physicians and health care providers have a duty before performing a procedure to provide adequate explanation to assist the patient’s decision-making process.

The physician or health care provider should provide a written or oral explanation about the proposed treatment or procedure, explained in a way the patient fully understands, which generally includes the following:

1. Diagnosis for which the treatment is proposed;
2. Nature of the treatment, procedure, medication, etc.;
3. Name, dosage and frequency of any prescribed medications;
4. Expected benefits;
5. Possible risks and side effects;
6. Availability of alternatives; and
7. Prognosis without proposed intervention.

When considering whether a patient can give informed consent, the legal requirements including capacity and information must be considered.

**Important note:** Having an intellectual disability does not automatically preclude an individual from being able to give informed consent, nor does the lack of a guardian or
conservator automatically mean an individual is capable of giving consent.

STEPS INVOLVED IN THE CONSENT PROCESS

A. DETERMINE CAPACITY

Capacity refers to a patient’s ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. It is question- and decision-specific and should be documented relative to each decision. Capacity to consent should be assessed and documented for each treatment or plan of treatment. An individual is presumed to have capacity to make a health care decision, to give or revoke an advance directive, and to designate or disqualify a surrogate.

Capacity is not static but can change over time or require distinct abilities depending on the nature and complexity of the specific treatment decision. Specific capabilities may be lost or gained at different times during the life of a patient with IDD. Capacity may even vary from day to day. For example, a patient in a postictal state may not be able to give consent but could several days later. Situations may arise where consent to a treatment has been given or refused on a patient’s behalf. However, if that patient then becomes capable of consenting to the treatment in the opinion of the health care practitioner, the patient’s own decision would take precedence over that of the SDM.

Assessed capacity can vary according to the supports provided. Involve the patient wherever possible by adapting the level and means of communicating to him/her; patients require functionally appropriate means of communication and support to realize their capacity for informed consent to, or refusal of, treatment. Offer information in a form you believe the patient will understand (e.g., pictures, symbols, gestures, vignettes). (See also Communicating Effectively.)

Involve others who know the patient best, such as family members or paid caregivers, to obtain information or to facilitate the patient’s understanding and communication.

If the patient is incapable of giving consent, or if there is uncertainty in this regard, follow appropriate legal procedures and ethical guidelines for assessing capacity. If incapable, delegate authority for decision making, which should be based on the patient’s best interests in the circumstances. Whenever possible, even when consent is obtained from a surrogate decision maker, assent should be sought from the patient and be documented.

B. OBTAIN AND DOCUMENT CONSENT

Consent must be given voluntarily: Allow sufficient time for the patient to
understand, consider the information, and ask questions. If the patient requests additional information, provide a timely response.

**Consent must be related to a proposed treatment and be informed by adequate disclosure:** The person obtaining consent should be knowledgeable and well-informed about the condition and proposed intervention.

**Consent must not be obtained through fraud, coercion or misrepresentation:** The patient should not be under any duress or pain. It is important to be familiar with how the individual usually exhibits pain (e.g., normal or unique pain responses), which may affect decisions.

**C. IDENTIFY THE CURRENT SURROGATE DECISION MAKER (SDM)**

A patient who lacks capacity to make or understand health care decisions cannot give consent, and the physician must get consent from someone else before rendering medical care except in an emergency. In this situation consent must be obtained from a health care agent or surrogate appointed by the patient while still competent in an advance directive. Consent may also be obtained by a judicially appointed conservator having authority to make health care decisions.

If the patient lacks capacity, and if an agent, patient-designated surrogate, or conservator has not been appointed or is not reasonably available, the physician may identify a surrogate to make health care decisions on behalf of the patient. The physician should choose someone who:

- knows about the person’s disability and condition,
- is actively involved in the person’s life,
- is willing and able to make the decision,
- will make the decision in the person’s interest,
- has no conflict of interest with the person.

Preference for the selection of the surrogate is given in the following order:

1. The patient’s spouse (unless legally separated)
2. The patient’s adult child
3. The patient’s parent or step-parent
4. The patient’s adult sibling
5. Any other adult relative of the patient
6. Any other adult who has exhibited special care and concern for the patient

If none of the individuals eligible to act as a surrogate are reasonably available, the
designated physician may make health care decisions for the patient after the designated physician either:

1. Consults with and obtains the recommendations of an institution’s ethics mechanism; or
2. Obtains concurrence from a second physician who is not directly involved in the patient’s health care, does not serve in a capacity of decision-making, influence, or responsibility over the designated physician, and is not under the designated physician’s decision-making, influence, or responsibility.

A surrogate must make health care decisions in accordance with the patient’s instructions, if any, and other wishes to the extent known to the surrogate. Otherwise, the surrogate makes decisions in accordance with the surrogate’s determination of the patient’s best interest.

D. WHEN IS INFORMED CONSENT REQUIRED?

As a general rule, informed consent should always be obtained. However, there may be situations where treatment can be administered without informed consent. The following guidelines generally apply when determining whether informed consent is required. These are guidelines and you should always check with your facility’s legal counsel if you have concerns.

Treatment/Procedures Requiring Informed Consent
Treatments and procedures requiring informed consent include, but are not limited to, the following:

1. Emergency or non-routine medical and dental procedures such as surgery, transfusions, and tooth extraction
2. Elective or therapeutic surgery
3. Any procedure requiring sedation and/or a general anesthetic
4. Medications having potential side effects that could create significant health risks
5. Diagnostic treatment, such as body tissue samples, studies of internal body organs and tissues that involve the injection of a dye or other solutions, and specialized X-rays such as the MRI
6. Cosmetic procedures involving invasive techniques, such as piercing of ear lobes
7. Participation in research

Treatment/Procedures Not Requiring Informed Consent
A patient’s legal representative(s) or family members should be consulted regarding
routine medical procedures, illness, or injury. The following procedures generally do not require a client’s formal consent:

1. The delivery of routine programs and services;
2. Emergency procedures necessary to address a significant threat to the client’s health when timely consent is not possible;
3. Routine medical procedures such as, but not limited to, injections, blood draws, sutures for lacerations, insertion of a heparin lock, and administration of medications that do not have potential life-threatening side effects; and
4. Reporting of HIV, hepatitis, potentially infectious diseases, and other notifiable conditions as required by law.

Also see:

INFORMED CONSENT CHECKLIST

Original tool: © 2011 Surrey Place Centre.
Developed by Gillis, G & Developmental Disabilities Primary Care Initiative Co-editors.

Adapted with permission of Surrey Place Centre. Revised by Elizabeth Setty Reeve, JD, Disability Rights Attorney/Intake Director, Disability Law & Advocacy Center of Tennessee, Nashville, TN.

This tool was also reviewed and adapted for U.S. use by physicians on this project’s Advisory Committee; for list, view here.

Additional reviewer was Matthew Holder, M.D., MBA, President-Elect, American Academy of Developmental Medicine and Dentistry, and Global Medical Advisor, Special Olympics.

RESOURCES:

- Tennessee Health Care Decisions Act at T.C.A. 68-11-1801 et seq.
- T.C.A. Title 33 Mental Health and Substance Abuse and Intellectual and Developmental Disabilities
- University of Tennessee Health Science Center’s A Guide for Health Care Providers in Tennessee (specifically the Consent and Advance Directives sections)
- The Arc Tennessee’s Conservatorship Guide
- Tennessee Medical Association Law Guide
Informed, Voluntary Consent Checklist and Sample Questions*

Inform the patient that you will be doing a capacity assessment with him/her. Do not assume that the patient will understand the connection between the illness and some consequent intervention.

Use the categories below to guide your assessment, and the examples below them if helpful.

- For each category of question, check Yes, No or Unsure.
- If the answer is No to any of these questions, the patient is not capable.

1. Does the patient understand that you are offering an intervention for a health problem?
   - Yes  No  Unsure
   - e.g., What problems are you having right now? What problem is bothering you most? Do you know why you are in the hospital/clinic?

2. Does the patient understand the nature of the proposed investigation or treatment and the expected benefits, burdens, and risks?
   - Yes  No  Unsure
   - e.g., What could be done to help you with your (specify health problem)? Do you think you are able to have this treatment? Do you know what might happen to you if you have this treatment? Do you know if this treatment can cause problems? Can it help you live longer?

3. Does the patient understand possible alternative treatment options and their expected benefits, burdens, and risks?
   - Yes  No  Unsure
   - e.g., Do you know different ways that might make you feel better?

4. Does the patient understand the likely effects of not having the proposed investigation or treatment?
   - Yes  No  Unsure
   - e.g., Do you know what could happen to you if you don't have this (specify treatment)? Could you get sicker or die if you don't have this (specify treatment)? Do you know what could happen if you don't have this (specify treatment)?

5. Is the patient free from any duress (e.g., illness, family pressure) or pain or distress that might impair his/her capacity regarding the particular decision? (Note that a relatively minor illness can cause significant anxiety.)
   - Yes  No  Unsure
   - e.g., Can you help me understand why you've decided to accept/refuse this treatment? Do you feel that you're being punished? Do you think you're a bad person? Is anyone telling you that you should or should not get this treatment?

6. Is the patient free from a mental health condition (e.g., mood disturbance or psychiatric illness) that may influence his/her capacity to give consent? (Note that having mental illness is not in itself an indicator of incapacity. This factor may change once the mental health condition is treated.)
   - Yes  No  Unsure
   - e.g., Are you hopeful about the future? Do you think you deserve to be treated? Do you think anyone is trying to hurt and/or harm you? Do you trust your doctor and nurse?

<table>
<thead>
<tr>
<th>CAPABLE</th>
<th>NOT CAPABLE</th>
<th>UNSURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>If &quot;YES&quot; to ALL of the above, and the patient can remember the information long enough to make a decision (verify by asking him/her to explain the information to you), then consider that capacity exists to consent to or refuse the proposed treatment.</td>
<td>If &quot;NO&quot; to ANY of the above, then repeat the questions; you may need to repeat this process several times to ensure that the patient understands. If the patient still does not understand, he/she is incapable and a legal Surrogate Decision Maker (SDM) should be assigned.</td>
<td>Consult family, if you have not already done so. Consider seeking a second opinion from: • A second physician who is not directly involved in the patient's health care. • Your facility's ethics mechanism if available.</td>
</tr>
</tbody>
</table>

*Questions adapted from: Etchells E. Joint Centre for Bioethics-Aid to Capacity Evaluation www.utoronto.ca/jcb
INFORMED, VOLUNTARY CONSENT CHECKLIST AND SAMPLE QUESTIONS

| Name: ________________________________ | DOB ___ / ___ / ___ |

| ASSESSMENT |

---

Date: ___ / ___ / ___  Print Name: ________________________________  Signature: ________________________________

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# CUMULATIVE PATIENT PROFILE

For adults with IDD

Adapted from template originally developed by the Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, and Electronic Medical Record, DFCM, St. Michael’s Hospital, Toronto

<table>
<thead>
<tr>
<th>Initial Assessment Completed: <em><strong>/</strong></em>/___</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider annual review, and update sooner when changes occur, e.g., decision-making capacity</td>
</tr>
<tr>
<td>Etiology of DD: ________________________</td>
</tr>
<tr>
<td>□ Definite □ Probable □ Possible □ Unknown</td>
</tr>
<tr>
<td>Genetic assessment: □ No □ Yes Date: <em><strong>/</strong></em>/___</td>
</tr>
<tr>
<td>Report on file? □ No □ Yes</td>
</tr>
<tr>
<td>Findings of genetic assessment:</td>
</tr>
<tr>
<td>Living situation:</td>
</tr>
<tr>
<td>□ Lives alone □ Lives with family □ Group home</td>
</tr>
<tr>
<td>□ Supported living □ Nursing Home □ Other</td>
</tr>
<tr>
<td>Last grade/degree completed:</td>
</tr>
<tr>
<td>Level of adaptive functioning:</td>
</tr>
<tr>
<td>□ Mild □ Moderate □ Severe</td>
</tr>
<tr>
<td>□ Profound □ Unknown</td>
</tr>
<tr>
<td>Approximate reading level:</td>
</tr>
<tr>
<td>Last/First Name: ________________________</td>
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<tr>
<td>Address: _______________________________</td>
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<tr>
<td>_______________________________</td>
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<tr>
<td>Phone: _______________ DOB <em><strong>/</strong></em>/___ Gender: ______</td>
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<tr>
<td>Medical Record Number: __________________</td>
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<tr>
<td>Psychological assessment: □ No □ Yes Date: <em><strong>/</strong></em>/___</td>
</tr>
<tr>
<td>Report on file? □ No □ Yes</td>
</tr>
<tr>
<td>Findings of psychological assessment:</td>
</tr>
</tbody>
</table>

## DECISION-MAKING CAPACITY

| Decision-Making Capacity: |
| □ Capable □ Not capable □ Unsure |
| Capacity to consent may vary over time and with the type of decision. Assess when proposing interventions for which consent is required. See Informed Consent Tool |
| Next of Kin: (If not Substitute Decision Maker): |
| Name: _______________________________ |
| Contact Information: _________________ |
| Substitute Decision Maker: |
| Name: _______________________________ |
| Contact Information: _________________ |
| How was the substitute decision maker chosen: |
| Others who may be helpful in decision making: |
| (e.g., Conservator/Guardian, Power of Attorney for Health Care, helpful agencies/support persons) |

## SPECIAL NEEDS AND COMMUNICATION

| Usual Clinic Visit Routines: |
| □ Prefers early day □ Prefers end of day |
| □ Limit time in waiting room □ Special positioning for exam |
| □ Extra staffing needed □ May require sedation |
| Tolerates venipuncture? □ No □ Yes |
| Other: _______________________________ |
| Triggers (e.g., trauma, noise, lighting, smells, color, textures): |
| Response Behaviors: |
| How to help: |
| Usual Response to Pain or Distress: |
| □ Typical □ Unique (describe): |
| Expressive Communication (method, devices): |
| Receptive Communication – prefers: |
| □ Pictures □ Simple explanations |
| □ Written □ Sign language |
| □ Other: _______________________________ |
| Usual Response to Medical Exam: |
| □ Fully/partially cooperates □ Fearful |
| □ Resistant □ Aggressive |
| Cautions (e.g., aggression, pica, aspiration risk): – specify modifications, precautions |
### PROBLEM LIST – Current Problems
(description, date identified, associated diagnoses)

<table>
<thead>
<tr>
<th>Date</th>
<th>Billing Code</th>
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</tbody>
</table>

### CURRENT MEDICATIONS

#### Name of Medication and Directions
(dose, route, frequency, any specific instructions)

Start Date

Asterisk (*) to indicate if prescription is refillable

<table>
<thead>
<tr>
<th>Start Date</th>
<th>Name of Medication and Directions</th>
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</thead>
<tbody>
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</table>
### RECORD OF PAST MEDICATIONS

<table>
<thead>
<tr>
<th>Start Date</th>
<th>Stop Date</th>
<th>Name of Medication and Directions (dose, route, frequency, specific instructions)</th>
<th>Comments</th>
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<tbody>
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</table>

**ALLERGIES** (include medications, food, stinging insect, pollen and dander, other)

<table>
<thead>
<tr>
<th>Allergy</th>
<th>Medication Reaction Type (allergy, side effect, exaggerated, other effect)</th>
<th>Reaction Severity (life threatening, major reaction, minor reaction, no reaction)</th>
<th>Status (confirmed, suspected)</th>
<th>Brief Description of the Reaction</th>
<th>Treatment Details (optional)</th>
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</tbody>
</table>
## Personal History

**Most important relationships:**

**Caregivers and supports:**

**Employment or Day Program (indicate total hours/week):**

**Leisure Activities:**

**Nutrition, Dietary:**

**Exercise:**

**Sexually active:**

- **Past**
  - □ No
  - □ Yes
  - □ Unknown

- **Current**
  - □ No
  - □ Yes
  - □ Unknown

## Risks

- **Tobacco**
- **Alcohol**
- **Street Drugs**
- **Behavior**

## Routine Health Maintenance

<table>
<thead>
<tr>
<th>Periodic Tests</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Comments or follow-up</th>
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<tbody>
<tr>
<td><strong>Vision</strong></td>
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<td><strong>Hearing</strong></td>
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<td><strong>Dental</strong></td>
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<tr>
<td><strong>Pap test</strong></td>
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<tr>
<td><strong>Colon cancer screening</strong></td>
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<tr>
<td><strong>Mammography</strong></td>
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<tr>
<td><strong>Bone Density</strong></td>
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</tbody>
</table>

### Advance Planning Needs:

- □ Transition
- □ Crisis
- □ Palliative
- □ End of Life
- □ DNR: if yes, record on file?

**Other:**

---

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HEALTH WATCH TABLE — FRAGILE X SYNDROME

Considerations

1. Head, eyes, ears, nose, throat
   - Children: Vision: strabismus, refractive errors are common
   - Hearing: recurrent otitis media is common
   - Nose: sinusitis is common
   - Adults: strabismus and refractive errors are common

2. Dental
   - Children and Adults: High arched palate and dental malocclusion are common

3. Cardiovascular
- **Children**: Mitral valve prolapse (MVP) is less common in children (~10%) but may develop during adolescence.

- **Adults**: MVP is common (~80%).
  - Aortic root dilation usually is not progressive.
  - Hypertension is common and exacerbated by anxiety.

4. **Sleep**

- **Children and Adults**: Obstructive sleep apnea (OSA) may be due to enlarged adenoids, hypotonia or connective tissue dysplasia.
- Sleep apnea is more common in individuals with Fragile X-associated tremor/ataxia syndrome.
- **Children and Adults**: Sleep-onset or sleep-maintenance insomnia is common.

- **Auscultate for murmurs or clicks at each visit**. If present, do an ECG and echocardiogram; refer to cardiologist, if indicated.

- Undertake an annual clinical exam. Based on findings, obtain an ECG and echocardiogram. Refer to cardiologist, as appropriate.

- Measure BP at each visit and at least annually.

- Treat hypertension when present.

5. **Gastrointestinal**

- **Children**: In infants, feeding problems are common with recurrent emesis associated with Gastroesophageal Reflux Disease (GERD) in ~30% of infants.

- **Refer for assessment of GERD**. Thickened liquids and upright positioning may be sufficient to manage GERD.
6. Genitourinary

- *Children and Adults:* Inguinal hernias are relatively common in males
- Macroorchidism generally develops in late childhood and early adolescence and persists
- Ureteral reflux may persist into adulthood
- Assess for inguinal hernia annually beginning at age 1 year
- Reassure patients and caregivers that macroorchidism does not require treatment
- Monitor for signs of urinary tract infections (UTI), screen with urinalysis.
- Evaluate recurring UTIs with cystourethrogram and renal ultrasound. Refer to a nephrologist.
- Consider and assess for a renal etiology, such as scarring, as the basis for persistent hypertension

7. Sexual function

- *Adults:* Males and females are fertile
- Consider discussion of recurrence risk and reproductive options as a basis for referral to a geneticist. Make such a referral even if Fragile X is only suspected so that molecular testing can be undertaken in the person concerned and relevant family members

8. Musculoskeletal (MSK)

- *Children & Adults:* Hyperextensible joints and pes planus are common. Scoliosis, clubfeet, joint dislocations (particularly congenital hip) may also occur
- Undertake an MSK exam at birth, then at each regularly scheduled checkup
- Elicit a history of possible dislocations
- Refer to an orthopedic surgeon as dictated by clinical findings
- Consider referral to a physical therapist (PT) or an occupational therapist (OT) to improve specific aspects of gross or fine motor skills if joint laxity or hypotonia interferes with function
- Consider referring to a physiotherapist and podiatrist for orthotics
9. Neurology

- *Children & Adults*: ~ 20% have epilepsy (may include generalized tonic-clonic seizures, staring spells, partial motor seizures, and temporal lobe seizures)
- Hypotonia is common, in addition to fine and gross motor delays
- Epilepsy occasionally persists into adulthood
- Ascertain a history of seizures, which usually present in early childhood
- Assess for atypical seizures in adulthood if suspicious findings occur or if intellectual function decreases
- Arrange an EEG if epilepsy is suspected from the history
- Refer to a neurologist as dictated by clinical findings

10. Behavioral/mental health

- *Children*: 70% - 80% are hyperactive; ~ 30% have autism
- Autistic-like features are common and may indicate concurrent autism spectrum disorder
- Anxiety and mood disorders can also be present
- Some features of autism, tantrums and aggression as well as anxiety and mood disorders may be treated with specific pharmacological agents
- Sensory defensiveness is common and may trigger problem behaviors
- Make an early referral to a clinical psychologist for essential parental teaching of appropriate behavior modification techniques following diagnosis
- Hyperactivity may be managed using stimulant medications after age 5 years
- Refer to an intensive behavioral intervention autism treatment program if autism spectrum disorder is present
- Consider a referral to a psychiatrist for possible mental health disorders
- Refer to a speech and language therapist following diagnosis

- *Adults*: Aggressive behavior, sensory defensiveness, attention deficit hyperactivity
- Consider referral to a psychiatrist or psychologist to assess and manage possible
disorder (ADHD), mood instability, and anxiety are common in adolescence and adulthood. Mental health disorders:
- Violent outbursts may occur, especially in males, and may respond to behavioral and/or pharmacological measures (as for children).

11. Endocrine

- **Children**: Precocious puberty may occur.
  - Include attention in clinical examination to signs of precocious puberty in females.
  - Refer to an endocrinologist for consideration of use of a gonadotropin agonist to manage precocious puberty.

- **Adults**: Premenstrual symptoms (PMS) may be severe.
  - Ascertain history of PMS with attention to menstruation, anxiety, depression, and mood lability. Consider a selective serotonin re-uptake inhibitor (SSRI) to stabilize mood if PMS symptoms are severe enough.

12. Other

- Occasionally presents as Prader-Willi syndrome-like phenotype.
- **Premutation Carriers**: A late onset tremor/ataxia syndrome has been reported in ~40% - 50% of male and ~8% of female Fragile X permutation carriers.
  - Premature ovarian failure by age 45 has been reported in ~20% - 40% of female Fragile X permutation carriers.
  - Psychiatric problems (e.g., mood and anxiety disorders) seem likely to occur in both
- For management of obesity and hyperphagia, consider approaches recommended for persons with Prader-Willi syndrome.
  - Refer to appropriate specialists (e.g., neurologist, endocrinologist, psychiatrist) as indicated to assist in managing Prader-Willi syndrome-like symptoms.
  - If premutation is suspected but not yet identified, order Fragile X DNA testing or refer to a genetics clinic.
  - To manage depression or anxiety in premutation carriers, SSRIs, regular exercise and counseling have been helpful.
male and female Fragile X premutation carriers\textsuperscript{1, 2}

Original tool: ©2011 Surrey Place Centre.
Developed by Forster-Gibson C, Berg J, & Developmental Disabilities Primary Care Initiative Co-editors.

**Expert Clinician Reviewers**
Thanks to the following clinicians for the review and helpful suggestions.

- Randi Hagerman, MD  
  Medical Director, M.I.N.D Institute  
  Endowed Chair in Fragile X Research, School of Medicine,  
  University of California, Davis, California

- Carlo Paribello, MD  
  Director, Fragile X Clinic, Surrey Place Centre, Toronto  
  President and Medical Director, Fragile X Research Foundation of Canada

Modified with permission of Surrey Place Centre. This tool was reviewed and adapted for U.S. use by physicians on the Toolkit’s Advisory Committee; for list, view [here](#).

Additional reviewer was Jeremy M. Veenstra-VanderWeele, M.D., Assistant Professor of Psychiatry, Pediatrics, and Pharmacology; Medical Director, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD); Director, Fragile X Treatment Research Program; Director, Division of Child and Adolescent Psychiatry, Vanderbilt University, Nashville.

**Resources**

- 10 published Fragile X syndrome health care guidelines reviewed and compared (For full list of references, see [www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx](http://www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx))

- Fragile X syndrome websites that may be helpful for families and caregivers
  - FRAXA Research Foundation  
    [www.fraxa.org](http://www.fraxa.org)
  - The National Fragile X Foundation  
  - Fragile X Research Foundation of Canada  
Behavioral/Emotional Concerns—Primary Care Provider Checklist
for Adults with Intellectual and other Developmental Disabilities (IDD)

Last/First Name: __________________________________________
Address: __________________________________________________
Phone: ___________________ DOB dd/mm/yyyy Gender: ___
Medical Record Number: ___________________________________

PART A: PRIMARY CARE PROVIDER SECTION

Date ___/___/___

Etiology of developmental disability, if known: ____________________________

Family history of:
☐ Medical disorders (specify) _________________________________
☐ Psychiatric disorders (specify) _________________________________

Additional disabilities:
☐ Autism spectrum disorder ☐ Hearing impairment
☐ Visual impairment ☐ Physical disability
☐ Other disability (specify): _________________________________
☐ Previous trauma ☐ Physical ☐ Emotional

Presenting Behavioral Concerns:

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

☐ Borderline ☐ Mild
☐ Moderate ☐ Severe
☐ Profound ☐ Unknown

Diagnostic Formulation of Behavioral Concerns:

Patient brought to family physician with escalating behavioral concerns

Individual communicating concerns verbally?

YES

Caregivers expressing concerns?

YES

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

YES

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

Check for concerns at next visit

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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 intellectual and other developmental disabilities. In some cases the only indicator of a medical problem may be a change in behavior or daily functioning. Consider a complete review of systems, a physical exam, and necessary investigations until the cause of the behavior 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 behavior disturbance (describe):

[ ] Other (specify):

**Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behavior change?**
- [ ] No  [ ] Yes  [ ] Possibly

**Assess/Rule out:**

- [ ] Medical condition giving rise to physical discomfort (e.g., rash or itch)
- [ ] Medication side effect
- [ ] Dysmenorrhea/Premenstrual syndrome
- [ ] Change in medication
- [ ] Peri-menopausal/menopausal (may start earlier)
- [ ] Allergies
- [ ] Musculoskeletal (arthritis, joints)
- [ ] Vision problem (e.g., cataracts)
- [ ] Osteoporosis
- [ ] Hearing problem
- [ ] Degenerative disc disease (DDD)
- [ ] Dental problem
- [ ] Spasticity
- [ ] Cardiovascular
- [ ] Neurological (e.g., seizures, dementia)
- [ ] Respiratory
- [ ] Dermatological
- [ ] Pneumonia
- [ ] Sensory discomfort (e.g., new clothes, shoes)
- [ ] GERD/Peptic ulcer disease/H.pylori infection
- [ ] Hypothyroidism
- [ ] Constipation, or other lower GI problems
- [ ] Diabetes (I or II)
- [ ] UTI
- [ ] Sleep problems/sleep apnea
- [ ] Other: ___________________________
**PART A: PRIMARY CARE PROVIDER SECTION**

Name: ___________________________  DOB ___ / ___ / ___

**2. PROBLEMS WITH COMMUNITY SUPPORTS OR EXPECTATIONS**

**Review Caregiver Information** *Identify possible problems with supports or expectations*

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress or change in the patient’s environment? (e.g., living situation, day program, family situation)</td>
<td>Do caregivers seem to have inappropriate expectations associated with:</td>
<td></td>
</tr>
<tr>
<td>Insufficient behavioral supports? Recognizing or adjusting to identified patient needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s disabilities not adequately assessed or supported? (e.g., sensory and communication supports for patients with autism) Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
<tr>
<td>Insufficient staff resources? (e.g., to implement treatment, recreational, vocational or leisure programs) Over- or under-estimating patient’s abilities (boredom or under-stimulation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inconsistencies in supports and staff approaches? Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
<tr>
<td>Insufficient training/education of direct care staff?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Comments:**

---

**3. REVIEW OF EMOTIONAL ISSUES**

**Review Caregiver Information** *Identify possible emotional issues*

**Summary and comments regarding emotional issues (e.g., related to change, stress, loss):**
PART A: PRIMARY CARE PROVIDER SECTION

Name: ___________________________ DOB ___ / ___ / ___

4. REVIEW OF POSSIBLE PSYCHIATRIC DISORDERS

History of diagnosed psychiatric disorder: □ No □ Yes Diagnosis: ___________________________

History of admission(s) to psychiatric facility: □ No □ Yes (specify): ___________________________

Summary and comments regarding symptoms and behaviors indicating possible psychiatric disorder:

____________________________________________________________________________________

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

Name: ______________________________ DOB __ __ __

MANAGEMENT PLAN

Use the "Diagnostic Formulation of Behavioral Concerns" to assess and treat causative or 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-language pathologist, occupational therapist, behavior analyst for assessments and recommendations regarding adaptive functioning, communication, sensory needs
   • e.g., genetic assessment/reassessment, psychiatric consult, functional behavioral assessment

5. Assessment and treatment and referral as indicated for
   • Supports and expectations
   • Emotional issues
   • Psychiatric disorder

6. Review behavioral strategies currently being used, revise as needed
   • De-escalation strategies
     – Use of a quiet, safe place
     – Safety response plan
   • Needed supports
   • Use of "as needed" (PRN) medications

7. Identify and access local resources for care of patient
   • Case management resources
   • Behavior therapist or behavior analyst
   • Other

8. Focus on behaviors
   • Identify target symptoms and behaviors to monitor
   • Institute use of Antecedent-Behavior-Consequence (ABC) Chart

9. Develop a written Crisis Prevention and Management Plan with caregivers and an interdisciplinary team
   • Applicable for all environments in which the behavior could occur, e.g., home, day program or community
   • Caregivers to monitor for triggers of behavior 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 involved, consider including ED staff in developing the Crisis Prevention and Management Plan

10. Regular and periodic medication review
    • Use Psychotropic Medications Checklist tool for review of psychotropic medications

Original tool: © 2011 Surrey Place Centre. Developed by Bradley, E & Developmental Disabilities Primary Care Initiative Co-editors. Modified and reformatted with permission of Surrey Place Centre. • This tool was reviewed and adapted for U.S. use by physicians on the Toolkit's Advisory Committee; for list, view here.
## Behavioral/Emotional Concerns—Caregiver Checklist

for Adults with Intellectual and other Developmental Disabilities (IDD)

<table>
<thead>
<tr>
<th>Last/First Name:</th>
<th></th>
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<tbody>
<tr>
<td>Address:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phone:</th>
<th>DOB</th>
<th>Gender:</th>
</tr>
</thead>
<tbody>
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<td>dd</td>
<td>mm</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medical Record Number:</th>
<th></th>
</tr>
</thead>
</table>

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

#### 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

### BEHAVIORAL PROBLEM

**When did the behavioral problem start?** _____/____/____

**Description of current difficult behavior(s):**

- [ ] Aggression to others
- [ ] Self-injurious behavior

**When was patient last “at his/her best”? (i.e., before these behavior problems) ____/____/____

**Has this sort of behavior happened before?**

- [ ] Yes
- [ ] No

**What triggers the behavior?**

- [ ] Risk?
  - [ ] To self
  - [ ] To others
  - [ ] To environment
  - [ ] Aggression to others
  - [ ] Self-injurious behavior

**And what do you (or other caregivers) do when the behavior occurs?**

- [ ] Severity of Damage or Injury
  - [ ] Mild (no damage)
  - [ ] Moderate (some)
  - [ ] Severe (extensive)

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

- [ ] Frequency of Distressing (Challenging) Behavior
  - [ ] More than once daily
  - [ ] Daily
  - [ ] Weekly
  - [ ] Monthly
## PART B: CAREGIVER SECTION

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

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:

---

### 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 behavior problems?

- [ ] No
- [ ] Yes

If yes, please specify or describe:

---

Could pain, injury or discomfort be contributing to the behavior 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 behavior disturbance (describe):

- [ ] Other (specify):

---

Are there any concerns about medications or possible medication side effects?
### PART B: CAREGIVER SECTION

**Name:** _________________________  **DOB** __/__/____

#### 2.1: CHANGES IN ENVIRONMENT before problem behavior(s) began

Have there been any recent changes or stressful circumstances regarding:
- [ ] 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 or work?

#### 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>Answer Options</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does this patient have a hearing or vision problem?</td>
<td>No/Yes</td>
<td>If yes, what is in place to help him/her?</td>
</tr>
<tr>
<td>Does this patient have a communication problem?</td>
<td>No/Yes</td>
<td>If yes, what is in place to help him/her?</td>
</tr>
<tr>
<td>Does environment seem too physically demanding for this patient?</td>
<td>No/Yes</td>
<td>If yes, do you think this patient’s environment is over-stimulating? under-stimulating? just right for this patient?</td>
</tr>
<tr>
<td>Does this patient have mobility problems or physical restrictions?</td>
<td>No/Yes</td>
<td>Does this patient have enough opportunities for appropriate physical activities?</td>
</tr>
<tr>
<td>If yes, does he/she receive physical therapy?</td>
<td>No/Yes</td>
<td>Are there any supports or programs that might help this patient and that are not now in place?</td>
</tr>
</tbody>
</table>

Caregiver comments:

---

If yes, please describe:
### PART B: CAREGIVER SECTION

**Name:** ________________________________  **DOB** ___ / ___ / ___

### 3: EMOTIONAL ISSUES
Please check (√) if any of these factors may be affecting this patient:

<table>
<thead>
<tr>
<th>Any recent change in relationships with significant others (e.g., staff, family, friends, romantic partner)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Additions (e.g., new roommate, birth of sibling)</td>
</tr>
<tr>
<td>□ Losses (e.g., staff change, housemate change)</td>
</tr>
<tr>
<td>□ Separations (e.g., decreased visits by volunteers, sibling moved out)</td>
</tr>
<tr>
<td>□ Deaths (e.g., parent, housemate, caregiver)</td>
</tr>
</tbody>
</table>

<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>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Sexual</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Exploitation</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
</tbody>
</table>

Comments: __________________________________________

□ Teasing or bullying
□ Being left out of an activity or group
□ Anxiety about completing tasks
□ Stress or upsetting event, at school or work
□ Issues regarding sexuality and relationships
□ Inability to verbalize feelings
□ Disappointment(s)
□ 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: __________________________________________

---

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: __________________________________________
PART B: CAREGIVER SECTION

Name: ____________________________ DOB ___ / ___ / ___

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 behavior 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.
Psychiatric Symptoms and Behavior Checklist

Checklist can be completed by primary care provider, or by caregiver and reviewed by provider

Please mark the list below:
No symptoms—0
Mild symptoms occasionally—1
Mild symptoms some of the time—2
Major symptoms some of the time—3
Major symptoms all of the time—4

<table>
<thead>
<tr>
<th>Symptoms and behaviors</th>
<th>BASELINE 1 Mark if usually present</th>
<th>NEW Mark if recent onset</th>
<th>COMMENTS If new onset or increased</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety-related</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phobias</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obsessive thoughts</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Compulsive behaviors</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Rituals/routines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood-related</td>
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<td></td>
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<tr>
<td>Agitation</td>
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<td></td>
<td></td>
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<tr>
<td>Irritability</td>
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<td></td>
</tr>
<tr>
<td>Aggression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Injurious behavior</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressed mood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of interest • Unhappy/miserable • Under-activity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating pattern</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Appetite</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Weight (provide details)</td>
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<td></td>
<td></td>
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<tr>
<td>Elevated mood</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Intrusiveness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypersexuality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotic-related 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotic and psychotic-like symptoms (e.g., self talk, delusions, hallucinations)</td>
<td></td>
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<tr>
<td>Movement-related</td>
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<tr>
<td>Catatonia ('Stuck')</td>
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<tr>
<td>Tics</td>
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<tr>
<td>Stereotypes (repetitive movements or utterances)</td>
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<tr>
<td>ADHD-related or Mood Disorder</td>
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<tr>
<td>Inattention</td>
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<tr>
<td>Hyperactivity</td>
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<td>Impulsivity</td>
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<tr>
<td>Dementia-related</td>
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<td>Concentration</td>
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<td>Memory</td>
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<tr>
<td>Other</td>
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<tr>
<td>Other</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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<td>Psychosomatic complaints</td>
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</tr>
</tbody>
</table>

1 Establish usual baseline i.e., behaviors and daily functioning before onset of concerns. 2 Use caution when interpreting psychotic-like symptoms and behaviors in patients with IDD. These may be associated with anxiety (or other circumstances) rather than a psychotic disorder.

Original tool: © 2011 Surrey Place Centre. Developed by Bradley, E & Developmental Disabilities Primary Care Initiative Co-editors. Funded by the Ontario Ministry of Community and Social Services and Ontario Ministry of Health and Long-Term Care, Surrey Place Centre and the Surrey Place Centre Charitable Foundation. Modified and reformatted with permission of Surrey Place Centre. • This tool was reviewed and adapted for U.S. use by physicians on the Toolkit’s Advisory Committee; for list, view here. • Reviewed also by Bruce Davis, PhD, BCBA-D, Sr. LPE, LPC, Director of Behavioral and Psychological Services, Tennessee Department of Intellectual and Developmental Disabilities, Nashville, TN.
DDPCI Health Care Transition Tools and Resources for Families and Caregivers of Youth with Developmental Disabilities

This document can be accessed on the Primary Care page of the Surrey Place Centre website: http://www.surreyplace.on.ca/primary-care

July 2014
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and Overview</td>
<td>1</td>
</tr>
<tr>
<td>Transition Readiness Checklist</td>
<td>5</td>
</tr>
<tr>
<td>The Transition Skills and Resources Toolkit</td>
<td>8</td>
</tr>
<tr>
<td>Criteria for Inclusion of Tools and Resources in this Toolkit</td>
<td>17</td>
</tr>
<tr>
<td>My List of Health Care Providers and Specialists</td>
<td>18</td>
</tr>
<tr>
<td>Portable Patient Profile – My Health Information</td>
<td>20</td>
</tr>
<tr>
<td>MyHealth 3-Sentence Summary</td>
<td>22</td>
</tr>
<tr>
<td>Family/Caregiver Guide to Organizing Health Information</td>
<td>23</td>
</tr>
<tr>
<td>Suggested Sections for Family/Caregiver Health Care Binder</td>
<td>24</td>
</tr>
<tr>
<td>Transportation Scheduler</td>
<td>26</td>
</tr>
<tr>
<td>Transfer of Care Plan: Paediatric to Adult Services</td>
<td>27</td>
</tr>
<tr>
<td>Person with Developmental Disabilities</td>
<td></td>
</tr>
<tr>
<td>References</td>
<td>29</td>
</tr>
</tbody>
</table>