The IDD Toolkit
Improving Health Care for Adults with Intellectual and Developmental Disabilities

April 24, 2015

Tom Cheetham MD, FAAIDD
Deputy Commissioner, Health Services
Tennessee Department of Intellectual and Developmental Disabilities
Presenter

- Achieved board certification in family medicine 1980
- Worked with people with IDD for over 30 years; 15 years of comprehensive community family practice
- Worked in the community and institutions:
  - 3 developmental centers
  - 24 bed dual diagnosis unit in state psychiatric hospital
- Academic appointments at 2 universities in Departments of Family Medicine with cross appointment in Department of Psychiatry
- Community education and consulting, including with community based dual diagnosis team
- Medical Director at Orange Grove Center, Chattanooga 2008-2009
- Deputy Commissioner, Office of Health Services TN DIDD and for previous year and a half also Deputy Commissioner, Child Health Department of Children’s Services
- Adjoint Assistant Professor of Developmental Disabilities at Vanderbilt University in Nashville
Learning Objectives

• Introduction to transition to adult intellectual disability medicine
• Development of clinical practice guidelines and tools
• General health tools
• Physical health tools
• Behavioral and mental health tools
• Questions
Introduction transition to adult ID medicine

Pediatrics

• Family focused
• Developmentally appropriate
• Parental involvement in decision making
• Multidisciplinary team

Adult Primary Care

• Patient focused
• Investigational
• Requires autonomous independent consumer skills
• Without many interdisciplinary resources

Intellectual/Developmental Disability Medicine 101
Examined 202 adults in Sydney Australia aged 20 – 50 years

- 95% had associated medical conditions
- on average 5.4 conditions per person
- saw physicians twice as often as controls
- but 42% of conditions previously undetected
- of those diagnosed half were inadequately managed
- almost 2 of 3 individuals reported no symptoms
- 24% of caregivers said there were no problems

Facts “On Hand” about Developmental Disability

1% General population is estimated to have a Developmental Disability

2 - 3x

2 - 3 times the physical health problems in comparison to the general population

4x

4x the number of prescriptions are written for individuals with developmental disabilities

1%

40 to 50%

behavioral or psychiatric diagnoses
TN’s Prescription Drug Problem (2010)

- 275.5 Million Hydrocodone Pills
  - 51 pills per every Tennessean over age 12

- 116.6 Million Xanax Pills
  - 22 pills per every Tennessean over age 12

- 113.5 Million Oxycodone Pills
  - 21 pills per every Tennessean over age 12

(Slide courtesy Dr. Michael Warren, TDH)
Patients

- Complex - different prevalence e.g., epilepsy 1% vs 40+%, constipation, etc.
- Comorbidities
- Atypical presentation of ill-health, including pain behavior
- Increased mortality
  - ♂ die 20 years younger than general population
  - ♀ die 13 years younger than general population
Adult IDD Medicine
Health Disparities

– Practitioners

• Little training or experience
• Lack communication skills
• Attitudes
• Diagnostic overshadowing
• Consent
• “Overwhelmed”
• Workload
• Reimbursement

(See e.g., Krahn & Fox; J Appl Res Intellect Disabil 2014; 27:431-446)
Numbers

Population of Tennessee
- est. 2015: 6,549,000
- 1% to 3%: 65,490 to 196,470

PCP panel of 2,000
- 1% to 3%: 20 to 60 patients

Challenging Behavior
- 40 to 50%: 8 to 30 patients
“Sometimes I Feel Overwhelmed”: Educational Needs of Family Physicians Caring for People with Intellectual Disability

Joanne Wilkinson, Deborah Dreyfus, Mary Cerreto, and Barbara Bokhour

Abstract

Primary care physicians who care for adults with intellectual disability often lack experience with the population, and patients with intellectual disability express dissatisfaction with their care. Establishing a secure primary care relationship is particularly important for adults with intellectual disability, who experience health disparities and may rely on their physician to direct/coordinate their care. The authors conducted semistructured interviews with 22 family physicians with the goal of identifying educational needs of family physicians who care for people with intellectual disability. Interviews were transcribed and coded using tools from grounded theory. Several themes related to educational needs were identified. Physician participants identified themes of “operating without a map,” discomfort with patients with intellectual disability, and a need for more exposure to experience with people with intellectual disability as important content areas. The authors also identified physician frustration and lack of confidence, compounded by anxiety related to difficult behaviors and a lack of context or frame of reference for patients with intellectual disability. Primary care physicians request some modification of their educational experience to better equip them to care for patients with intellectual disability. Their request for experiential, not theoretical, learning fits well under the umbrella of cultural competence (a required competency in U.S. medical education).

Key Words: health; medical education; primary care; health disparities; communication
DD Primary Care Initiative: Consensus Guidelines

• **Developed**: Colloquium, Toronto (November 7 – 11, 2005)

• **Published**: *Canadian Family Physician* (November 2006)

• **Updated**: *Canadian Family Physician* (May 2011)
Canadian Consensus Guidelines for the Primary Care of Adults with DD (2011)

31 guidelines, 74 evidence-ranked recommendations:

- General issues (9)
- Physical health issues (12)
- Behavioural and mental health issues (10)
Primary care of adults with developmental disabilities
Canadian consensus guidelines

William F. Sullivan MD CCP MD Joseph M. Berg MD MSC ED MFMFP FCOG
Espeth Bradley MD MBBS FRCP FCOG
Tobin Cheatham MD CCP Richard Denton MD CCP FCOG PFRMS John Heng MA Brian Hennessey MD MD CCP
David Joyce MD CCP Maureen Kelly RN MA Marika Kossoy Yona Lunsiey MD Ocyh Shirley McMillan RN MN CDON

Abstract

Objective To update the 2006 Canadian guidelines for primary care of adults with developmental disabilities (DD) and to make practical recommendations based on current knowledge to address the particular health issues of adults with DD.

Quality of evidence Knowledgeable health care providers participating in a colloquium and a subsequent working group discussed and agreed on revisions to the 2006 guidelines based on a comprehensive review of publications, feedback gained from users of the guidelines, and personal clinical experiences. Most of the available evidence in this area of care is from expert opinion or published consensus statements (level III).

Main message Adults with DD have complex health issues that are different from those of the general population. This guideline identifies the particular health issues faced by adults with DD and provides recommendations to improve their quality of life, to improve health care, and to prevent suffering, morbidity, and mortality. These guidelines synthesize general, physical, behavioral, and mental health issues of adults with DD that medical providers should be aware of, and they present recommendations that practitioners can apply. Because of interacting biologic, psychological, and social factors that contribute to the health and well-being of adults with DD, these guidelines emphasize involving caregivers, adapting procedures when appropriate, and seeking input from a range of health care professionals when available. Ethical care is also emphasized. The guidelines are formulated within an ethical framework that pays attention to issues such as informed consent and the assessment of health benefits in relation to risks of harm.

Conclusion Implementation of the guidelines proposed here would improve the health of adults with DD and would minimize disparities in health and health care between adults with DD and those in the general population.

Résumé

Objectif Mettre à jour les lignes directrices canadiennes de 2006 sur les soins primaires aux adultes ayant une déficience développementale (DD) et présenter des recommandations pratiques fondées sur les connaissances actuelles pour traiter des problèmes de santé particuliers chez des adultes ayant une DD.

Qualité des preuves Des professionnels de la santé expérimentés participant à un colloque et un groupe de travail subseqment ont discuté et convenu des révisions aux lignes directrices de 2006 en se fondant sur une recherche documentaire exhaustive, la rétrospection des utilisateurs

This article has been peer reviewed.
Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2011;57:541-53

La traduction en français de cet article se trouve à www.ccfp.ca dans la table des matières du numéro de mai 2011 à la page e154.
General issues (9)

1. Disparities exist **poorer health, increased morbidity and mortality**
2. Etiology of DD **useful, informs preventive care or treatment**
3. Adaptive functioning **may decline or improve; basis for care and supports**
4. Pain and distress **may be atypical; non-specific behavioural changes**
5. Multiple or long term use of some medications **may cause harm**
6. Abuse and neglect **occur frequently, often by known persons**
7. Capacity for voluntary and informed consent **varies with complexity and circumstances**
8. Advanced care planning **can make positive difference to transitions, crisis and end-of-life care**
9. Interdisciplinary health care **effective for complex needs of individuals with DD**
10. Physical inactivity and obesity prevalent with adverse outcomes, health promotion program

11. Vision and hearing impairments often underdiagnosed, can result in substantial behaviour and adaptive functioning changes

12. Dental disease one of most common health problems, behaviour change

13. Cardiac disorders prevalent, some have congenital heart disease

14. Respiratory disorders aspiration and pneumonia, swallowing difficulties prevalent, obstructive sleep apnea

15. Gastrointestinal and feeding problems common, often present differently
16. Sexuality *an important issue, often not considered in adolescents and adults*

17. Musculoskeletal disorders *scoliosis, contractures and spasticity occur frequently, result in reduced mobility and activity*

18. Epilepsy *prevalent, often difficult to recognize, evaluate and control, has pervasive impact*

19. Endocrine disorders *can account for changing clinical presentations*

20. Immunization *a crucial part of preventive care, people with limited reading skills may not have access to public health programs*

21. Cancer screening *an essential aspect of preventive care, less likely to be included in preventive screening programs*
 Behavioural and mental health guidelines (10)

- 22. Problem behaviours *cause of aggression and self-injury often not psychiatric illness*
- 23. Psychiatric disorders *more common, may be inappropriately addressed, mistakenly thought to be typical*
- 24. Psychotic disorders *difficult to diagnose, delusions and hallucinations can not expressed verbally, imaginary friends*
- 25. Input and assistance from individuals with DD and their caregivers *are vital for understanding problem behaviour, emotional disturbance, psychiatric disorders*
- 26. Interventions other than medication *are usually effective in presenting or alleviating problem behaviours*
27. Psychotropic medications effective for diagnosed psychiatric disorders
28. Antipsychotic medications effective for diagnoses psychotic disorders or schizophrenia but should not be used without this diagnosis as routine treatment of problem behaviours
29. Behavioural crises occasionally arise, may need management in emergency department
30. Dementia important to diagnose early especially specialized services in Down syndrome (at increased risk), diagnosis may be missed, need baseline
31. Alcohol or drug abuse less common, more difficulty moderating intake and accessing
Developmental Disabilities Health Care E-Toolkit

The Vanderbilt Kennedy Center UCEDD and LEND, University of Tennessee Boling Center UCEDD and LEND, and the Tennessee Department of Intellectual and Developmental Disabilities were awarded a one-year Special Hope Foundation Grant in 2012, to develop an electronic Health Care Toolkit, an adaptation of Canadian Primary Care tools.
Acknowledgements

Janet Shouse  
Program Coordinator  
Developmental Disabilities Health Care E-Toolkit  
Vanderbilt Kennedy Center  
janet.shouse@Vanderbilt.Edu  
615-875-5080

and the entire Advisory Team:  
Joanie Crowley, self-advocate  
Jim Crowley, parent  
Elisabeth Dykens, PhD  
Debra Hanna, MD  
Evon Lee, PhD  
Beth Ann Malow, MD  
Fred Palmer, MD  
Tyler Reimschisel, MD  
Sherry Robbins, MD  
Jan Rosemergy, PhD  
Jessica Solomon, 4th year VU Medical Student
www.iddtoolkit.org

The IDD Toolkit is a website that provides information for the primary care of adults with intellectual and developmental disabilities.

The Toolkit offers health care providers best-practice tools and information regarding specific medical and mental and behavioral health concerns of adults with intellectual and developmental disabilities, including resources for patients and families. The Toolkit is also accessible on smartphones and tablets.

Toolkit Contents
- GENERAL ISSUES
  - Communicating Effectively
  - Informed Consent
  - Informed Consent Checklist
  - Office Organizational Tips
  - Today's Visit Form
- PHYSICAL HEALTH ISSUES
  - Cumulative Patient Profile
  - Female Preventive Care Checklist
  - Male Preventive Care Checklist
- CHECKLISTS—Disability Specific
- BEHAVIORAL AND MENTAL HEALTH ISSUES
- RESOURCES

The IDD Toolkit was made possible by a grant from the Special Hope Foundation, Palo Alto, CA. The Toolkit is an adaptation for U.S. use of tools developed by the Developmental Disabilities Primary Care Initiative (2009-2014), Surrey Place Center, Toronto, Canada. The toolkit was adapted for U.S. use in a project funded by a grant from Special Hope Foundation to the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. Advisory Committee members included physicians from the Tennessee Department of Intellectual and Developmental Disabilities, Vanderbilt University, and the University of Tennessee Billing Center for Developmental Disabilities. Photos ©Stocksphoto.com and ©Microstock Corporation, 05/14

Health Care for Adults with Intellectual and Developmental Disabilities

Toolkit for Primary Care Providers
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

It is 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
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.

Informed Consent

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
# Cumulative Patient Profile

## CUMULATIVE PATIENT PROFILE

For adults with ID

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>
<th>Last/First Name: ____________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider annual review, and update sooner when changes occur, e.g., decision-making capacity</td>
<td>Address: ____________________________________</td>
</tr>
<tr>
<td>Etiology of DD: _________________________</td>
<td>Phone: __________________________ DOB <em><strong>/</strong></em>/___</td>
</tr>
<tr>
<td>□ Definite □ Probable □ Possible □ Unknown</td>
<td>Gender: _________________________________</td>
</tr>
<tr>
<td>Genetic assessment: □ No □ Yes Date: <strong><strong>/</strong></strong></td>
<td>Medical Record Number: ______________________</td>
</tr>
<tr>
<td>Report on file? □ No □ Yes</td>
<td>Psychological assessment: □ No □ Yes Date: <strong><strong>/</strong></strong></td>
</tr>
<tr>
<td>Findings of genetic assessment:</td>
<td>Report on file? □ No □ Yes</td>
</tr>
<tr>
<td>Findings of psychological assessment:</td>
<td></td>
</tr>
</tbody>
</table>

## DECISION-MAKING CAPACITY

<table>
<thead>
<tr>
<th>Decision-Making Capacity:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Capable □ Not capable □ Unsure</td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Next of Kin: (if not Substitute Decision Maker):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: ____________________________</td>
</tr>
<tr>
<td>Contact Information: ____________________________</td>
</tr>
</tbody>
</table>

## SUBSTITUTE DECISION MAKER

<table>
<thead>
<tr>
<th>Substitute Decision Maker:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: ____________________</td>
</tr>
<tr>
<td>Contact Information: ____________________</td>
</tr>
<tr>
<td>How was the substitute decision maker chosen:</td>
</tr>
</tbody>
</table>

## 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

<table>
<thead>
<tr>
<th>Usual Clinic Visit Routines:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Prefers early day □ Prefers end of day</td>
</tr>
<tr>
<td>□ Limit time in waiting room □ Special positioning for exam</td>
</tr>
<tr>
<td>□ Extra staffing needed □ May require sedation</td>
</tr>
<tr>
<td>Tolerates venipuncture? □ No □ Yes</td>
</tr>
<tr>
<td>Other: ____________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Triggers (e.g., trauma, noise, lighting, smells, color, textures):</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Response Behaviors:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to help:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Usual Response to Pain or Distress:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Typical □ Unique (describe):</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expressive Communication (method, devices):</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Receptive Communication – prefers:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Pictures □ Simple explanations</td>
</tr>
<tr>
<td>□ Written □ Sign language</td>
</tr>
<tr>
<td>□ Other: ____________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Usual Response to Medical Exam:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Fully/partially cooperates □ Fearful</td>
</tr>
<tr>
<td>□ Resistant □ Aggressive</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cautions (e.g., aggression, pica, aspiration risk): – specify modifications, precautions</th>
</tr>
</thead>
</table>
Health Watch Table
Fragile X Syndrome

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>refractive errors are common</td>
<td>screening and an auditory brainstem response (ABR)</td>
</tr>
<tr>
<td>Hearing: recurrent otitis media is common</td>
<td>Refer for a comprehensive ophthalmologic examination by 4 years of age</td>
</tr>
<tr>
<td>Nose: sinusitis is common</td>
<td>Visualize tympanic membranes at each visit</td>
</tr>
</tbody>
</table>

- Adults: strabismus and refractive errors are common
- Undertake hearing and vision screening at each visit with particular attention to myopia and hearing loss

2. Dental

- Children and Adults: High arched palate and dental malocclusion are common
- Refer to a dentist for a semi-annual exam

3. Cardiovascular
Cheetham’s Checklist

1. First, blame the **drugs**.
2. Is this person **constipated**?
3. Does he/she have **gastroesophageal reflux (GERD)**?
4. Could the behavior be a **seizure**?
5. Is he/she **aspirating**?
6. What’s the **etiology** of the intellectual disability – does he/she have a syndrome?
7. Is his/her behavior **different from usual**?
8. How would we know if he/she is **having pain**?
9. How is he/she **sleeping**?
10. How’s the person **eating? / dental?** (added May 2012 to 2001 version)
11. Is there a **psychiatric disorder** present?
Cheetham’s Checklist 2.

10. Is there a psychiatric disorder present?

THINK:

- **anxiety** disorder
- depression
- bipolar **mood disorder**
- obsessive-compulsive disorder (OCD)
- posttraumatic stress disorder (PTSD)
- Tourette’s disorder
- personality disorder

**before**

- schizophrenia
- other psychosis
Cheetham’s Checklist 3.

10. Is there a psychiatric disorder present?

I don’t have a clue!

(But I have ruled out a medical problem... I think...)

TRY:

i) anti-anxiety (anxiolytic)

ii) antidepressant

iii) mood stabilizer

iv) *lastly* antipsychotic drug
Behavioral/Emotional Concerns – Primary Care Provider Checklist

Patient brought to family physician with escalating behavioral concerns

- Individual communicating concerns verbally?
- NO
  - Caregivers expressing concerns?
  - NO
    - Should there be concerns? (Is anyone at risk?)
    - NO
      - Check for concerns at next visit
    - YES
      - Medical condition?
        - NO
          - Problem with supports/Expectations?
          - NO
            - Emotional issues?
            - NO
              - Psychiatric disorder?
              - NO
                - YES: Treat disorder
              - YES: Address issues
            - YES: Adjust supports or expectations
          - YES: Treat condition
        - YES
          - YES: Treat disorder

© Bradley & Summers, 1999; modified in 2009
Behavioral/Emotional Concerns — Caregiver Checklist

for Adults with Intellectual and other Developmental Disabilities (IDD)

<table>
<thead>
<tr>
<th>Last/First Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Phone:</td>
</tr>
<tr>
<td>DOB: / / / Gender:</td>
</tr>
<tr>
<td>Medical Record Number:</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>What type of developmental disability does the patient have (i.e., what caused it?) (e.g., Down syndrome, Fragile X syndrome).</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the patient's level of functioning?</td>
</tr>
<tr>
<td>□ Borderline</td>
</tr>
<tr>
<td>□ Mild</td>
</tr>
</tbody>
</table>

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

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

Risk?

- □ To self
- □ To others
- □ To environment

Aggression to others

- □ Self-injurious behavior

Severity of Damage or Injury

- □ Mild (no damage)
- □ Moderate (some)
- □ Severe (extensive)

Frequency of Distressing (Challenging) Behavior

- □ More than once daily
- □ Daily
- □ Weekly
- □ Monthly
# 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</th>
<th>NEW</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety-related</td>
<td>Mark if usually present</td>
<td>Mark if recent onset</td>
<td>If new onset or increased</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>
</tr>
<tr>
<td>Compulsive behaviors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rituals/routines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elevated mood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intrusiveness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypersensitivity</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>
<td></td>
<td></td>
</tr>
<tr>
<td>Movement-related</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catatonia (‘stuck’)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stereotypes (repetitive movements or utterances)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADHD-related or Mood Disorder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inattention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyperactivity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impulsivity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia-related</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concentration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol misuse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug abuse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual issues/problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosomatic complaints</td>
<td></td>
<td></td>
<td></td>
</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 psychiatric disorder.

Original tool © 2011 Surrey Place Centre. Developed by Bradley, I & 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

Health Care Transition Tools and Resources

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
Thank you!

www.tn.gov/didd

thomas.cheetham@tn.gov