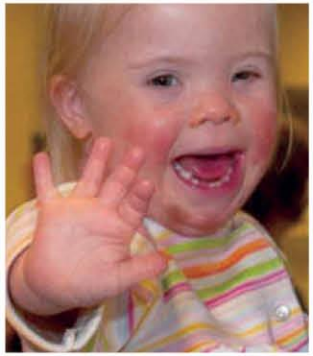
VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES





Improving Access to Health Care for People with Disabilities with the IDD Toolkit

Janet Shouse,
Program Coordinator, IDD Toolkit
Vanderbilt Kennedy Center,
June 2, 2017

First, a Little About Janet

This is my son Evan. He is:

- 21 years old
- Has a twin
- Has autism
- Has little language
- Has behavior challenges

My Background

- Spent nearly 30 years as a newspaper copy editor
- Became active in the disability community shortly after Evan's diagnosis at age 2
- Joined the Vanderbilt Kennedy Center in 2010 as a parent-mentor in the Parent Stress Intervention Project
- Joined the Developmental Disabilities Health Care IDD Toolkit Project in 2013
- Also joined TennesseeWorks, a grant to improve the employment landscape for people with disabilities, in 2014 and write a weekly blog called *Rise to Work*

The Vanderbilt Kennedy Center for Research on Human Development

- Intellectual and Developmental Disabilities Research Center
- University Center for Excellence in Developmental Disabilities
- Leadership Education in Neurodevelopmental Disabilities
- Treatment and Research Institute for Autism Spectrum Disorders

So, Why Do We Need the IDD Toolkit?

People with IDD face health disparities

- Complex, difficult-to-treat and more frequent medical conditions
- Difficulties expressing symptoms and pain
- Atypical presentation of ill-health
- Difficulty accessing health care, either physically or financially, or both
- Inadequate or inappropriate health care
- Little or no preventive care

Concerns of Practitioners

- May have little training or experience with adults with IDD
- May worry about patients' lack of communication
- Attitudes about people with disabilities
- "Diagnostic overshadowing"
- Issues of consent
- "Overwhelmed"
- Reimbursement issues

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

Creation of the IDD Toolkit

- Vanderbilt Kennedy Center UCEDD and LEND, University of Tennessee Boling Center UCEDD and LEND, and the Tennessee Department of Intellectual and Developmental Disabilities
- Awarded a Special Hope Foundation Grant in 2013
- Develop an electronic Health Care Toolkit, an adaptation Canada's "Tools for the Primary Care of People with Developmental Disabilities."

Creation of the IDD Toolkit

- Dr. Tom Cheetham worked in several large institutions in Ontario, Canada.
- As institutions closed, Ontario created the Developmental Disabilities Primary Care Initiative, which included Dr. Cheetham.
- Consensus Guidelines led to “Tools for the Primary Care of People with Developmental Disabilities.”
- Dr. Cheetham was instrumental in helping us get permission for the adaptation of the Canadian tools.

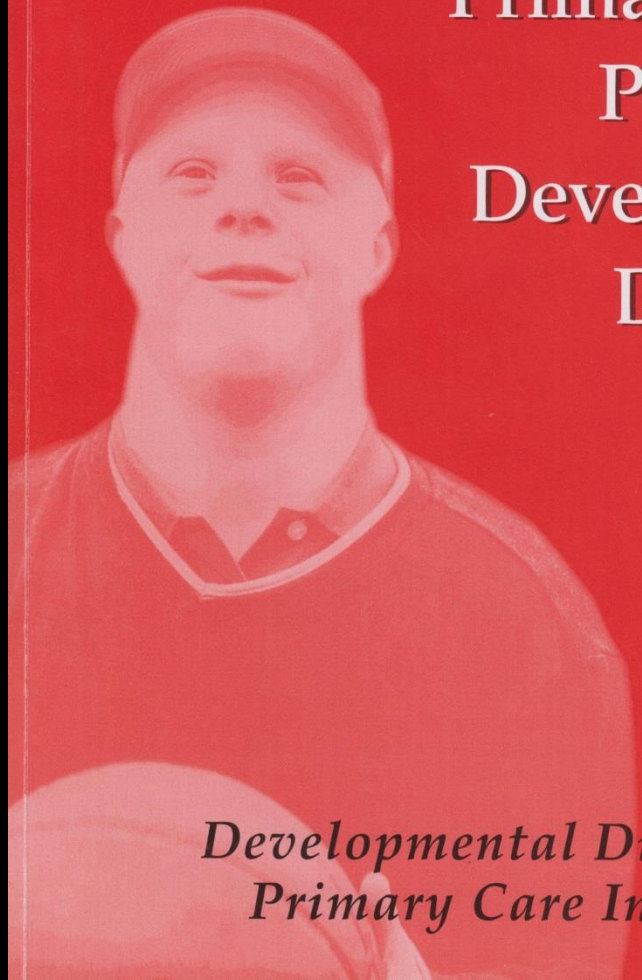
Dr. Tom Cheetham,
Deputy Commissioner
of Health Services for DIDD

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? / any dental issues?**
11. Is there a **psychiatric disorder** present?

2011 Edition

Tools for the Primary Care of People with Developmental Disabilities



Developmental Disabilities Primary Care Initiative

Why Did We Need To Adapt the Tools?

- Easily accessible on the Internet
- Responsive whether on a laptop, tablet or smart phone
- Language differences—developmental disabilities has a different meaning in Canada
- Includes sections Americans with Disabilities Act and U.S. guidelines on informed consent
- Provides U.S. and international resources

Some Quick Facts from Google Analytics

- 121,908 sessions
- 102,934 users
- 321,174 page views
- 2.63 pages per session
- Users from 184 countries have accessed site
- Various Toolkit forms have been downloaded more than 296,000 times

So, somebody is finding useful information on the IDD Toolkit site. Maybe you can, too!

HEALTH CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Toolkit for Primary Care Providers

GENERAL ISSUES

- Communicating Effectively
- Informed Consent
- Informed Consent Checklist
- Adaptive Functioning and Different Levels of IDD
- Office Organizational tips
- Today's Visit Form

PHYSICAL HEALTH ISSUES

- Cumulative Patient Profile
- Female Preventive Care Checklist
- Male Preventive Care Checklist

- Down Syndrome
- Fetal Alcohol Spectrum Disorder (FASD)
- Fragile X Syndrome
- Prader-Willi Syndrome
- Williams Syndrome
- 22q11.2 Deletion Syndrome

BEHAVIORAL AND MENTAL HEALTH ISSUES

- Initial Management of Behavioral

These tools, except for Autism table, were developed by the Developmental Disabilities Primary Care Initiative (DDPCI) (2005-2014), Surrey Place Centre, Toronto, Canada, funded by Ontario Ministry of Community and Social Services and Ontario Ministry of Health and Long-Term Care, Surrey Place Centre, and Surrey Place Centre Charitable Foundation. The DDPCI published Tools for the Primary Care of People with Developmental Disabilities to complement the Primary care of adults with developmental disabilities: Canadian consensus guidelines. All tools © 2011 Surrey Place Centre. Adapted for use in the U.S. by the

www.iddtoolkit.org

ONLINE TRAINING IS AVAILABLE USING

THE FOLLOWING LINKS

- For health care professionals, training entitled "Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care". (Free CME credit is offered upon completion).

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- Initial Management of Behavioral Crises in Primary Care

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- Similar free online training for

What's in the Toolkit?

General Issues

- Communicating effectively
- Informed consent
- Office organizational tips
- Adaptive functioning and levels of IDD
- Cumulative patient profile
- Today's Office Visit

Name: _____ DOB ___ / ___ / ___

INFORMED, VOLUNTARY CONSENT CHECKLIST AND SAMPLE QUESTIONS[a]

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*) done?
Could you get sicker or die if you don't have this (*specify treatment*)?
Do you know what could happen if you 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

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Physical Health

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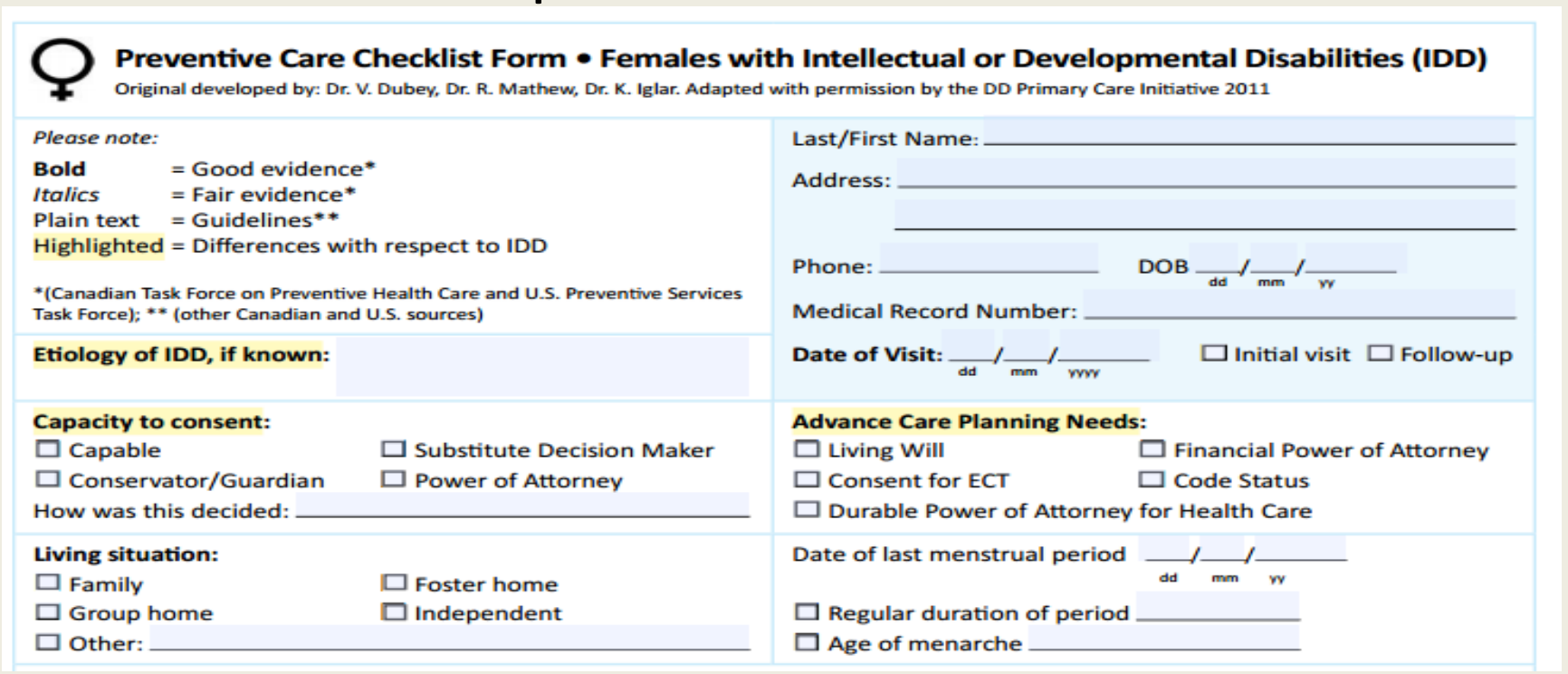
- Female preventive care checklist
- Male preventive care checklist



Preventive Care Checklist Form • Females with Intellectual or Developmental Disabilities (IDD)

Original developed by: Dr. V. Dubey, Dr. R. Mathew, Dr. K. Iglar. Adapted with permission by the DD Primary Care Initiative 2011

Please note:

Bold = Good evidence*
Italics = Fair evidence*
Plain text = Guidelines**
Highlighted = Differences with respect to IDD

*(Canadian Task Force on Preventive Health Care and U.S. Preventive Services Task Force); ** (other Canadian and U.S. sources)

Last/First Name: _____

Address: _____

_____

Phone: _____ DOB ____/____/_____ (dd/mm/yy)

Medical Record Number: _____

Etiology of IDD, if known:

Date of Visit: ____/____/_____ (dd/mm/yyyy) ☐ Initial visit ☐ Follow-up

Capacity to consent:

☐ Capable ☐ Substitute Decision Maker
☐ Conservator/Guardian ☐ Power of Attorney
How was this decided: _____

Advance Care Planning Needs:

☐ Living Will ☐ Financial Power of Attorney
☐ Consent for ECT ☐ Code Status
☐ Durable Power of Attorney for Health Care

Living situation:

☐ Family ☐ Foster home
☐ Group home ☐ Independent
☐ Other: _____

Date of last menstrual period ____/____/_____ (dd/mm/yy)

☐ Regular duration of period _____
☐ Age of menarche _____

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Last/First Name: _____

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_____

Phone: _____ DOB ___/___/_____ (dd mm yy)

Medical Record Number: _____

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Date of Visit: ___/___/_____ (dd mm yyyy) ☐ Initial visit ☐ Follow-up

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☐ Other: _____

Date of last menstrual period ___/___/_____ (dd mm yy)

☐ Regular duration of period _____
☐ Age of menarche _____

Lifestyle/Habits

☐ Underweight
☐ Overweight
☐ Exercise
☐ Alcohol
☐ Illicit Drugs
☐ *Sexual History*

☐ Diet _____
☐ Tobacco use packs/day ___ date quit ___/___/_____
☐ Sleep _____
☐ Family _____
☐ Relationships (recent changes?) _____
☐ Day Program/Work _____
☐ Contraception/Family Planning _____

Current Concerns

_____

Review of Systems

	Normal	Remarks
	☐	

Review of Systems

	Normal	Remarks
	☐	

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Health Watch Tables

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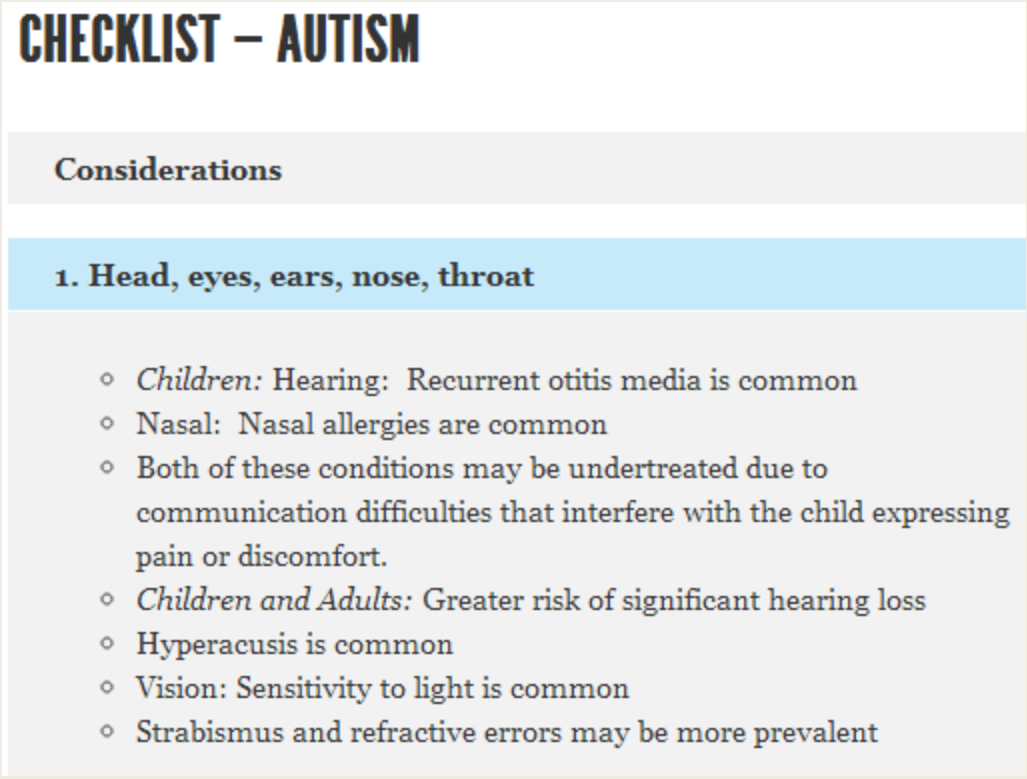

CHECKLIST – AUTISM

Considerations

1. Head, eyes, ears, nose, throat

- *Children:* Hearing: Recurrent otitis media is common
- Nasal: Nasal allergies are common
- Both of these conditions may be undertreated due to communication difficulties that interfere with the child expressing pain or discomfort.
- *Children and Adults:* Greater risk of significant hearing loss
- Hyperacusis is common
- Vision: Sensitivity to light is common
- Strabismus and refractive errors may be more prevalent

HEALTH WATCH TABLE – FRAGILE X SYNDROME

Considerations	Recommendations
1. Head, eyes, ears, nose, throat	
○ *Children: Vision:* strabismus, refractive errors are common ○ *Hearing:* recurrent otitis media is common ○ *Nose:* sinusitis is common	○ Undertake newborn vision and hearing screening and an auditory brainstem response (ABR) ○ Refer for a comprehensive ophthalmologic examination by 4 years of age ○ Visualize tympanic membranes at each visit
○ *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	
○ *Children:* Mitral valve prolapse (MVP) is less common in children (~10%) but may develop during adolescence	○ Auscultate for murmurs or clicks at each visit. If present, do an ECG and echocardiogram; refer to cardiologist, if indicated

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	○ Ascertain a sleep history, examining bedtime, waketime, time needed to fall asleep and possible waking throughout the night ○ Assess for evidence of OSA ○ Refer to a sleep specialist, as appropriate ○ Behavioral sleep interventions or supplemental melatonin may be helpful
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.

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BEHAVIORAL AND MENTAL HEALTH ISSUES

- Initial Management of Behavioral Crises in Primary Care
- Risk Assessment Tool for Adults with IDD in Behavioral Crisis
- Behavioral Problems and Emotional Concerns-Provider Checklist
- Behavioral Problems and Emotional Concerns-Caregiver Checklist
- Psychiatric Symptoms and Behaviors Checklist
- ABC (Antecedent-Behavior-Consequence) Chart
- Crisis Prevention and Management Planning
- Crisis Prevention and Management Form
- Psychotropic Medication Issues
- Psychotropic Medications Checklist

REFERENCES

RESOURCES

- Tips and Resources Fact Sheets

Developmental Disabilities Health Care E-Toolkit Project.

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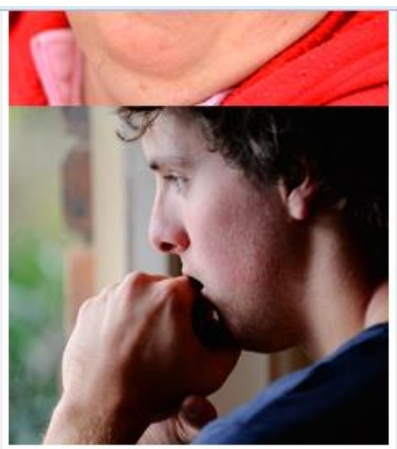
- Similar free online training for individuals with IDD, their families, conservators, and other caregivers. The modules are in 8- to 15-minute segments that can be completed independently as your schedule permits.



What's in the Toolkit?

Behavioral and Mental Health Issues

- Initial Management of Behavioral Crises in Primary Care
- Risk Assessment Tool for Adults with IDD in Behavioral Crisis
- Behavioral Problems and Emotional Concerns-Provider Checklist
- Behavioral Problems and Emotional Concerns-Caregiver Checklist
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- ABC (Antecedent-Behavior-Consequence) Chart
- Crisis Prevention and Management Planning
- Crisis Prevention and Management Form
- Psychotropic Medication Issues
- Psychotropic Medications Checklist

Behavioral/Emotional Concerns—Caregiver Checklist

for Adults with Intellectual and Other Developmental Disabilities (IDD)

Last/First Name: _____

Address: _____

_____

Phone: _____ DOB ___/___/___ (dd/mm/yyyy) Gender: ____

Medical Record Number: _____

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? ___/___/___

When was patient last "at his/her best"? (i.e., before these behavior problems) ___/___/___

Description of current difficult behavior(s):

_____

Has this sort of behavior happened before?

_____

What triggers the behavior?

_____

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

_____

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

Examining a Behavioral Problem

- When did the behavioral problem start?
- When was patient last “at his/her best”?
- Description of current difficult behavior(s):
- Has this sort of behavior happened before?
- What triggers the behavior? And what do you (or other caregivers) do when the behavior occurs?
- What, in the past, helped or did not help to manage the behavior? (include medications or trials of medications to manage behavior[s])

PART B: CAREGIVER SECTION

Name: _____ DOB ___ / ___ / ___

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):

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?

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 problem with **sensory triggers?**

☐ 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?

_____

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 physical therapy?

☐ No ☐ Yes

Are there **any supports or programs that might help this patient** and that are not now in place?

☐ No ☐ Yes

If yes, please describe:

_____

Caregiver comments:

PART B: CAREGIVER SECTION

Name: _____ DOB ___ / ___ / ___

3: EMOTIONAL ISSUES Please check (V) 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**
- ☐ **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)**
  (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:

_____

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: _____

Behavioral/Emotional Concerns—Primary Care Provider Checklist

for Adults with Intellectual and other Developmental Disabilities (IDD)

Last/First Name: _____

Address: _____

_____

Phone: _____ DOB ___/___/___ Gender: ____
dd mm yyy

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) _____

Presenting Behavioral Concerns:

Additional disabilities:

☐ Autism spectrum disorder ☐ Hearing impairment

☐ Visual impairment ☐ Physical disability

☐ Other disability (specify): _____

☐ Previous trauma ☐ Physical ☐ Emotional

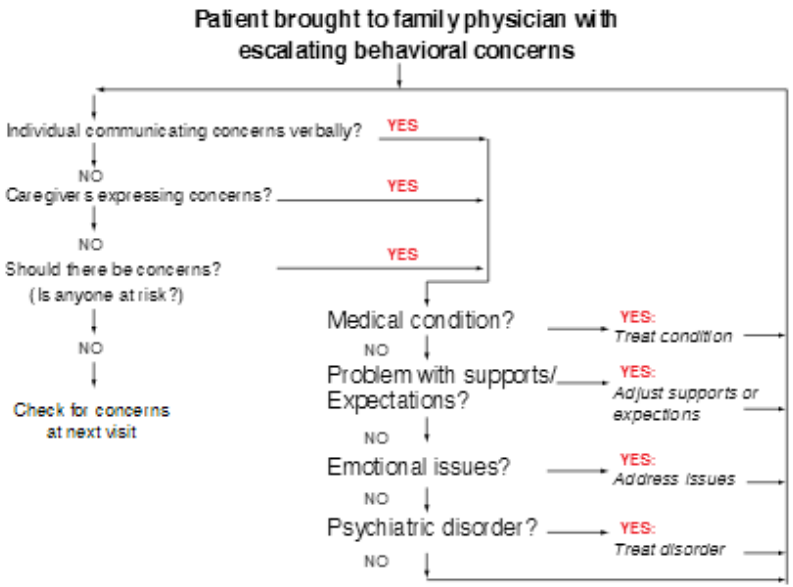
What is the patient's most recent level of functioning on formal assessment? Year done: _____

☐ Borderline ☐ Mild

☐ Moderate ☐ Severe

☐ Profound ☐ Unknown

Diagnostic Formulation of Behavioral Concerns:



Psychiatric Symptoms and Behavior Checklist

Name: _____

DOB ___/___/___

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

Symptoms and behaviors	BASELINE [1] Mark if usually present	NEW Mark if recent onset	COMMENTS If new onset or increased
Anxiety-related			
Anxiety			
Panic			
Phobias			
Obsessive thoughts			
Compulsive behaviors			
Rituals/routines			
Other			
Mood-related			
Agitation			
Irritability			
Aggression			
Self-injurious behavior			
Depressed mood			
Loss of interest • Unhappy/miserable • Under-activity			
Sleep issues			
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			

Crisis Prevention and Management Plan

for Adults with Intellectual and other Developmental Disabilities (IDD) at Risk of or During Behavioral Crises

Crisis Plan for:

Name: _____

DOB ___/___/___

Date: _____

A Crisis Prevention and Management Plan for an adult patient with IDD addresses serious behavior problems and helps prevent, or prepare for, a crisis. It describes how to recognize the patient's pattern of escalating behaviors. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioral crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behavior escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient should go to the Emergency Department (ED).

(See example of completed Crisis Prevention and Management Plan below.)

Problem behavior:

Stage of Patient Behavior	Recommended Caregiver Responses
Normal, calm behavior	**Use positive approaches, encourage usual routines**
Stage A: Prevention *(Identify early warning signs that signal increasing stress or anxiety.)*	**Be supportive, modify environment to meet needs** *(Identify de-escalation strategies that are helpful for this patient).*

Example of Completed Crisis Prevention and Management Plan

Crisis Plan for:

Name: Jack Doe

DOB 02/20/1952

Date: 05/13/2010

Problem behavior: Verbal threats, swearing, physical aggression

Stage of Patient Behavior	Recommended Caregiver Responses
Normal, calm behavior Talks well about work, people, follows routine, enjoys others, laughs, good rapport with peers. Prefers quiet; dislikes loud noises from radio, TV.	**Use positive approaches, encourage usual routines** Positive instructions (when you do… then you can…); joke with Jack; clear directions; reinforcement for pleasant conversation about work, others; following routine; being proud of himself.
Stage A: Prevention *(Identify early warning signs that signal increasing stress or anxiety.)* • Complaining about work or co-worker or anyone he has had contact with on arrival at the group home. • Says that they shouldn't be able to do that or they didn't follow the rules.	**Be supportive, modify environment to meet needs** *(Identify de-escalation strategies that are helpful for this patient with DD).* 1. Take Jack to quiet room. Talk with him about what is wrong. (What happened? How does he feel? Illness?) 2. Ask him to develop a solution (with your help, if necessary) – what will make it better? 3. Have him write down the problem and solution for later reference when he thinks about it again. Continue to redi-rect verbally with positive words. 4. Reinforce any calm behaviors. *Go to next stage* if behavior escalates.
Stage B: Escalation *(Identify signs of the patient with DD escalating to a possible behavioral crisis.)* • Swearing about people or situations in a loud voice and pacing (walking back and forth from one end of the living room or hallway to the other without stopping).	**Be directive** (use verbal direction and modelling), **continue to modify environment to meet needs, ensure safety** 1. Ask Jack to sit; sit with him (remember distance). 2. Ask to help him discuss or read the solution he wrote earlier. 3. Ask if there is another problem. Resolve. 4. Have him engage in relaxation techniques, e.g., breathing slowly with you. If he refuses to comply, follow direction or escalates, go to *next stage*.
***PRN: Administer the PRN if Jack swears and paces for five continuous minutes (Stage B) or refuses to calm down and breathe slowly with staff member (Stage C) after two requests.**	
Stage C: Crisis *(Risk of harm to self, others, or environment, or seriously disruptive behavior, e.g., acting out.)* • Throwing objects at the walls or floors. • Jack's pacing becomes quicker and he begins to dart toward things, grabs them and throws them. • Threatening bodily harm and hitting/ kicking others and saying demeaning words or swearing (e.g., "Get out of my way you _____ or I'll hit you.")	**Use safety and crisis response strategies** 1. Keep critical distance. Put something between you and Jack; ensure you have an exit. 2. Say "Stop, Jack, time to calm down, breathe with me" (model breathing). If no reduction/refusal, say, "Jack, stop, I'm calling people to help." 3. Remove or tell others to leave the area. 4. Leave the area – call *9-1-1*. 5. Have patient taken to ED by ambulance, with *Essential*

PSYCHOTROPIC MEDICATION ISSUES

OVERVIEW

Primary care of adults with developmental disabilities: Canadian consensus guidelines (2011) addresses several issues related to psychotropic medication use in this population.

- Problem behavior, such as aggression and self-injury, is not a psychiatric disorder but might be a symptom of a health-related disorder or other circumstance (e.g., insufficient supports). Problem behaviors sometimes occur because environments do not meet the needs of the adult with IDD. Despite the absence of an evidence base, psychotropic medications are regularly used to manage problem behaviors among adults with IDD. Canadian consensus guidelines state that antipsychotic drugs should not be regarded as a routine treatment of problem behaviors in adults with IDD. (However, the U.S. Food and Drug Administration has approved the use of risperidone and aripiprazole in the treatment of irritability associated with autism spectrum disorders in children ages 6 to 17.)

- Interventions other than medications are often effective for preventing or alleviating problem behaviors. These may include psychological or behavioral therapy, environmental modification, communication aids or addressing

Name: _____ DOB ___ / ___ / _____ Medical Record Number: _____

PSYCHOTROPIC MEDICATION CHECKLIST*

1. Has the patient been given a psychiatric diagnosis?	☐No ☐Yes ☐Not Sure
2. Is an interdisciplinary assessment indicated for the concerns for which the medication is being used?	☐No ☐Yes ☐Not Sure
3. Is medication treatment consistent with the diagnosis?	☐No ☐Yes ☐Not Sure
4. If patient does not have a psychiatric diagnosis and is being treated for "behavior problems," are guidelines for problem behaviors being followed?	☐No ☐Yes ☐Not Sure
5. Has valid informed consent been obtained for the current treatment plan?	☐No ☐Yes ☐Not Sure
6. Are there further medical assessments that need to be done to clarify a diagnosis or to ensure appropriate medication monitoring?	☐No ☐Yes ☐Not Sure
7. Have target behaviors against which to monitor medication effectiveness been defined so that they can be objectively measured?	☐No ☐Yes ☐Not Sure
8. Is the patient being regularly monitored for side effects?	☐No ☐Yes ☐Not Sure
9. Are PRN and STAT doses of medications being used excessively?	☐No ☐Yes ☐Not Sure

Comments/Action Plan (for issues flagged):

HEALTH WATCH TABLES

- Autism
- Down Syndrome
- Fetal Alcohol Spectrum Disorder (FASD)
- Fragile X Syndrome
- Prader-Willi Syndrome
- Williams Syndrome
- 22q11.2 Deletion Syndrome

BEHAVIORAL AND MENTAL HEALTH ISSUES

- Initial Management of Behavioral Crises in Primary Care
- Risk Assessment Tool for Adults with IDD in Behavioral Crisis
- Behavioral Problems and Emotional Concerns-Provider Checklist
- Behavioral Problems and Emotional Concerns-Caregiver Checklist
- Psychiatric Symptoms and Behaviors Checklist
- ABC (Antecedent-Behavior-Consequence) Chart
- Crisis Prevention and Management Planning
- Crisis Prevention and Management Form
- Psychotropic Medication Issues
- Psychotropic Medications Checklist

REFERENCES

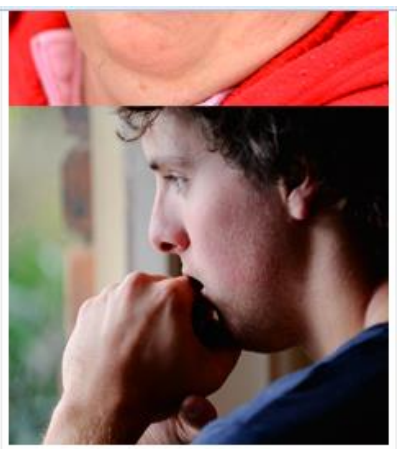
RESOURCES

- Tips and Resources Fact Sheets

Developmental Disabilities Health Care E-Toolkit Project.

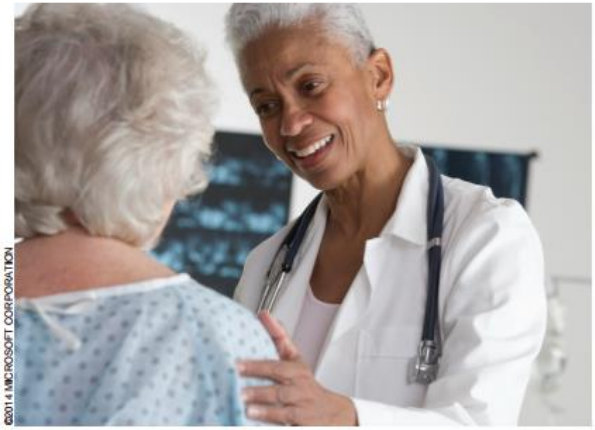
ONLINE TRAINING IS AVAILABLE USING THE FOLLOWING LINKS

- For health care professionals, training entitled "Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care". (Free CME credit is offered upon completion).
- Similar free online training for individuals with IDD, their families, conservators, and other caregivers. The modules are in 8- to 15-minute segments that can be completed independently as your schedule permits.



Going To The Doctor*

TIPS FOR INDIVIDUALS WITH DISABILITIES



Going to the doctor is important, because it gives you an opportunity to ask questions about your body and to stay healthy. This tip sheet will explain why people go to the doctor and what to expect before, during, and after a visit.

Common reasons for going to the doctor

- General checkup to stay healthy
- Feeling sick but do not know why
- To be treated for an illness, injury, or surgery
- To get a physical exam for school, camp, or work

Keeping the appointment

It is very important to keep your appointment. Some doctors may even charge you if you do not keep an appointment. If something comes up that makes it impossible for you to keep it, be sure to call the doctor's office as soon as you know to cancel the appointment and to get a new time and date.

The day of the appointment

Try to get to the doctor's appointment about 15 minutes early. Be sure to bring:

- Your insurance card, if you have one
- Payment for the visit
- Your list of questions for the doctor
- Something to do in case you have to wait

When you get to the doctor's office

Let the receptionist know you have arrived. You may be asked to sign your name on a paper and write down the time you arrived. The receptionist may ask to see your insurance card, or ask you how you will pay for your visit. You will wait in the waiting room until your name is called. If the doctor is late, it is because he or she is helping someone else who had an appointment before you. Be patient.

Resources include Tip Sheets, one for patients, one for support staff, and one for clinicians

"Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care"

Free Online Training Series

- One for health care professionals, including physicians, advanced practice nurses, pharmacists, psychologists, and social workers. *(AMA, AAFP and APA credit is awarded upon completion.)*
- One for families, conservators and other caregivers, including direct support professionals.
- Both offer 90 minutes of training in eight 10- to 15-minute modules, which can be viewed independently.
- A short pre-test and post-test for each module helps to ensure understanding of key concepts.

An Interesting Tidbit on How the Training Began

Training Modules

1 – Introduction

2 – Communication

3 – Common Physical Health Issues

4 – An Approach to Challenging Behavior

5 – Autism Spectrum Disorder

6 – Non-pharmacologic treatments for challenging behavior

7 – Psychotropic Medications, Part 1

8 – Psychotropic Medications, Part 2

Now, we're going to see if my video works!

Family and Caregiver Training

vkc.mc.vanderbilt.edu/healthtraining

Prescriber Training

http://tinyurl.com/Vu-train-idd-meds

(CME credits of 1.5 for AMA, APA and AAFP)

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- Tom Cheetham, MD
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- Elisabeth Dykens, PhD
- Kylie Beck
- Jon Tapp

Questions or Comments?

Thank You!

Contact
Janet
Shouse
at
615-875-8833
or
janet.shouse@vanderbilt.edu