Health Care for Adults With Intellectual and Developmental Disabilities (I/DD)

Learning Objectives

At the end of this educational activity, participants should be able to:

• Identify physical and social barriers to promoting preventative health care in adults with I/DD

• Describe potential areas where HCPs might misdiagnose treatable illness in adults with I/DD, and discuss strategies to address these high-risk circumstances
Outline

• Foundational study on health issues in adults with intellectual and developmental disabilities (I/DD)
• Define prevention and discuss differences with this population
• Review evidence on common health issues
• Consider how misdiagnosis is possible

How can I apply this tomorrow with members?

Medical Disorders of Adults With Mental Retardation: A Population Study

Examined 202 adults in Sydney, Australia
– 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

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**Why focus on prevention?**

- Experience health care disparities
- Often receive poor care but expensive care – different patterns of health needs, undetected and unmanaged issues
- Also experience barriers to prevention activities
- Secondary prevention important (primary prevention is limited)
- Members who experience poor quality of life and early death

**What are we trying to prevent?**

- Primary prevention – prevent the disease from happening (e.g., folate supplement during pregnancy)

- Secondary prevention – detect the disease before signs/symptoms are evident (e.g., healthy diet, exercise, do not smoke)

- Tertiary prevention – reduce the effects of the known disease (e.g., regular eye examinations in a member with diabetes)
What are we trying to prevent?

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US Preventive Services Task Force

Independent organization with focus on prevention with evidence-based recommendations for primary care

- clinical preventive services for asymptomatic people
- evidence based
- recommendations are graded A (highest) through D (lowest) based on strength of evidence and balance of harm vs benefit of screening
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Multiple physical and mental health comorbidity in adults with intellectual disabilities (ID)

- Primary health care data on 1,424,378 adults in 314 practices in Scotland
- 8,014 had ID
  - Multimorbidity was greater (ID and 2 or more conditions)
  - Occurred at much earlier age
  - Profile of health conditions differed
  - No association with neighborhood deprivation
- Conclusion: people with ID need focused services irrespective of where they live and at a much earlier age

Cooper et al., *BMC Family Practice* (2015) 16:110
Key findings from Cooper et al.

• Physical health conditions
  – 14/32 significantly more prevalent
    • epilepsy (Odds Ratio 31.03), constipation (OR 11.19), visual impairment (OR 7.81)
    • more than twice as likely: hearing loss, eczema, dyspepsia, thyroid disorders, Parkinson’s Disease or Parkinsonism
  – 11/32 significantly less prevalent
    • coronary heart disease, peripheral vascular disease, hypertension, atrial fib, any cancer in last 5 years, COPD
  – 7/32 no significant difference

• Mental health conditions
  – 5/6 significantly more prevalent
    • schizophrenia/bipolar (OR 7.16), anxiety (OR 2.62), depression (OR 1.88)
    • depression was most prevalent 15.8% compared to 10.1% in general population
  – 1/6 no significant difference (anorexia/bulimia)
  – dementia – proportion of people with ID who had dementia was small but occurred at much earlier age
• Deprivation showed no effect
• Comorbidity at ages 20-25 similar to 50-54 in general population
Atlas on the Primary Care of Adults with Developmental Disabilities [i.e., ID] in Ontario

• To understand health care issues at population level Ontario Canada
• Study linked data between health sector and social services sector
• 2 sections:
  – health status and health care patterns
  – quality of primary care with focus on preventive care and chronic disease management
• Total number of adults with DD = 66,484

Lunsky Y, Klein-Geltink JE, Yates EA eds. Institute for Clinical Evaluative Sciences and Center for Addiction and Mental Health, 2013. Available at www.ices.on.ca

Key findings from Lunsky et al.

• Accessed primary care at equal or greater rates
• Most common disease was psychiatric disorders – 48.6% affected which was almost twice general population
• Congestive heart failure – more than 3 times
• COPD – almost twice
• Diabetes – 60% higher

• Vulnerable to medically complex and co-occurring health problems
• Require greater primary care coordination, specialist and hospital care
Key findings from Lunsky et al. continued

- **Utilization**
  - more likely to visit Emergency Departments and be hospitalized
  - preventable hospitalizations age 25 to 34 years almost 10 times higher and age 30 to 39 years were 13 times higher
  - only 20% were receiving care through interdisciplinary teams

- **Secondary prevention**
  - 22% received periodic health examination over a 2 year period
  - low uptake of preventive care
  - less likely to be screened for colorectal (age 50-64 years), breast (50-64 years) and cervical cancer (age 20-64 years)

Key findings from Lunsky et al. continued

- **Chronic disease management**
  - less likely to have bone mineral density testing within 1 year of low trauma fracture

- **Medications**
  - almost 1 in 2 were dispensed multiple medications at one time
  - 1 in 5 were receiving 5 or more medications concurrently – regular follow up with same family physician didn’t occur for 32%
  - antipsychotics most common medication – dispensed to 21%
  - 1 in 5 who were prescribed antipsychotics were dispensed 2 or more concurrently
Health Disparities

Patients
- Complex - different prevalence of health conditions e.g., epilepsy 1% vs 40+%, constipation, etc.
- Co-morbidities
- Atypical presentation of ill-health, including pain behavior
- Diagnosis can be difficult and presentation may be late in course of illness
- Physical and mental/behavioral health issues intertwined
- Increased mortality

Increased Mortality
- State IDD Service Systems
  Average age at death
  male  61.8 years
  female  59.2 years
- Medicaid Claims Data
  Average age at death
  male  63.3 years
  female  61.7 years
- U.S. Population
  male  76.4 years
  female  81.2 years

Associated health problems in psychiatric inpatients with ID

Retrospective chart review of admissions acute care specialized psychiatric unit  
N = 198 individuals

- 56% males, mean age 39 years
- mild intellectual disability 46%, moderate ID 40%, severe ID 13%
- reason for admission: aggression, self-injury, property destruction, loud outbursts

40% had physical health issue and 73% were on antipsychotics on admission


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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)
Barriers

- **Physical**
  - transportation
  - accessible office
  - accessible exam room and table
  - non-ambulatory/non-weight bearing members
  - mammography equipment
  - mobility limitations due to spasticity or contractures

Barriers

- **Social (in addition to Practitioners Health Disparities)**
  - diagnostic overshadowing i.e., attributing all behavior to the ID
  - attitudes, including office staff, especially with dual diagnosis (ID and psychiatric diagnosis or challenging behavior)
  - member’s understanding and/or willingness to cooperate – past trauma (trauma informed care)
So how does this help me tomorrow with members in the clinic?
Cheetham’s Checklist 1

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?
11. Is there a psychiatric disorder present?

All the mistakes I’ve made over the years and want to share so you don’t make them too

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Cheetham’s Checklist 1

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www.tn.gov/didd

Click on Health Services: look under Video Learning

9. How is he/she **sleeping**?
11. Is there a **psychiatric disorder** present?
Primary care of adults with developmental disabilities
Canadian consensus guidelines

William J. Santenio, MD, Joseph M. Berg, MD, Mark A. Koopman, PhD, BC-PMCH, DCH, FRCPC

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 evidence to address the particular health issues of adults with DD.

Quality of evidence: Knowledgeable health care primary physicians and a clinical leader for the field were engaged to develop the guidelines. A chart review for any literature relevant to primary care of adults with DD was conducted. Current literature was then reviewed, with emphasis on RCTs and systematic reviews, and key topics were compiled into a draft of the guidelines. The guidelines were then reviewed and updated in a series of 2-week meetings held in February 2011. The draft guidelines were then reviewed by health care primary physicians and a clinical leader for the field, with feedback gained from users of the guidelines.

Clinical experiences: Based on the available evidence, we have outlined the main factors involved in the primary care of adults with DD and have provided recommendations on how to best address these factors.

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

Ricard:

M. Santenio à Jacques E. Fernald pour les soins de santé des adultes avec des troubles de développement (DD) et pour promouvoir l'implantation de services spécialisés de santé mentale pour les adultes avec DD.

M. Santenio dévoile les résultats de la consultation avec les experts qui se sont prononcés pour reformer le système de santé et diminuer la disparité de santé entre les adultes avec DD et ceux de la population générale.

This article has been peer reviewed.

Can Fam Physician 2011;57:541-53.
HEALTH CARE FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Tailored for Primary Care Providers

GENERIC ISSUES
- Communication Effective
- Optimum Weight
- Informed Parental Decision
- Adaptive Functioning and Difficulties (i.e. ODD)
- Effective Medication Use

PHYSICAL HEALTH ISSUES
- Osteoporosis
- Perimenopausal Care

HEALTH RISK FACTORS
- Autism
- Chronic Illness
- ADHD

The Health Care for Intellectual and Developmental Disabilities (HCID) toolkit has four sections:

1. General Issues
2. Physical Health Issues
3. Health Risk Factors
4. Tailored for Primary Care Providers

Each section is designed to help providers address the unique challenges faced by individuals with intellectual and developmental disabilities. The toolkit includes guidelines, best practices, and resources to support comprehensive care.

For the latest updates and additional resources, visit the HCID website at [www.hcid.org](http://www.hcid.org).
### Health Water Table — Trisomy Syndrome

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Feeding, eye, ear, nose, throat</strong></td>
<td></td>
</tr>
<tr>
<td>+ Children:</td>
<td>+ Underestimate webster test and hearing screening and an early positive response (ABR)</td>
</tr>
<tr>
<td></td>
<td>+ Refer to a comprehensive otolaryngologic examination by 5 years of age</td>
</tr>
<tr>
<td></td>
<td>+ Place where children are common</td>
</tr>
<tr>
<td>+ Adults: hearing and vision screening at each visit with periodic attention to neuropathy and hearing loss</td>
<td></td>
</tr>
<tr>
<td><strong>2. Dental</strong></td>
<td></td>
</tr>
<tr>
<td>+ Children and adults: High arch palate and occlusal malocclusion are common</td>
<td></td>
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<tr>
<td>+ Refer to a dentist for a semi-annual exam</td>
<td></td>
</tr>
<tr>
<td><strong>3. Cardiac</strong></td>
<td></td>
</tr>
<tr>
<td>+ Children: Mitral valve prolapse (MVP) is less common in children under 1 year of age but may develop during adolescence</td>
<td></td>
</tr>
<tr>
<td>+ Adults: MVP is common</td>
<td></td>
</tr>
<tr>
<td>+ Aortic root dilatation usually not progressive</td>
<td></td>
</tr>
<tr>
<td>+ Hypertension is common and exacerbated by anxiety</td>
<td></td>
</tr>
<tr>
<td>+ Auscultate for mitral valve at each visit. If present, do an ECG and echocardiogram; refer to cardiologist. If indicated</td>
<td></td>
</tr>
<tr>
<td><strong>4. Sleep</strong></td>
<td></td>
</tr>
<tr>
<td>+ Children and Adults: Obstructive sleep apnea (OSA) may be due to enlarged adenoids, hypotonia or connective tissue disorder</td>
<td></td>
</tr>
<tr>
<td>+ Sleep apnea is more common in individuals with fragile X-associated tremor/ataxia syndrome</td>
<td></td>
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<tr>
<td>+ Children and Adult: Sleep-onset or sleep maintenance insomnia is common</td>
<td></td>
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<tr>
<td>+ Assess a deep history, unusual bedtimes, and behavioral sleep problems</td>
<td></td>
</tr>
<tr>
<td>+ Obstructive sleep apnea can be diagnosed by overnight sleep study or polysomnography</td>
<td></td>
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<tr>
<td>+ Refer to a specialist, as appropriate</td>
<td></td>
</tr>
<tr>
<td>+ Behavioral sleep interventions or supplemental testosterone may be helpful</td>
<td></td>
</tr>
<tr>
<td><strong>5. Gastrointestinal</strong></td>
<td></td>
</tr>
<tr>
<td>+ Children: In infants, feeding problems are common with recurrent reflex associated with gastroesophageal reflux disease (GERD) in 30% of infants</td>
<td></td>
</tr>
<tr>
<td>+ Refer for assessment of GERD. Pneumonial liquids or apical positioning may be necessary (GERD)</td>
<td></td>
</tr>
</tbody>
</table>
Thank you!

www.iddtoolkit.org

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www.tn.gov/didd
look under Health Services – Video Learning
Have you seen this patient?

A 22-year-old man with intellectual disability, limited verbal skills, and difficulty staying asleep at night, with frequent awakenings with wandering to the kitchen. Unable to stay awake during the day, alternating with outbursts marked by loud screaming and nonsensical speech. His caregivers are increasingly frustrated especially with his waking up others at his group home.

What additional questions do you have about his sleep?

Sleep “101” (Basics of Sleep Medicine)

- What time is bedtime?
- How long does it take him to fall asleep?
- What time does he start waking up?
- What time does he wake up for good in the morning?
- Does he snore?
- What happens in his night wakings?
- Is he overweight? Obese?
- Family history of sleep disordered breathing?
Medical Conditions in Adults with Autism Spectrum Disorder (ASD)

Table 2. Health Conditions in Adults with Autism Spectrum Disorders and in the General Population

<table>
<thead>
<tr>
<th>Health Condition</th>
<th>18-29 years</th>
<th>30-59 years</th>
<th>&gt; 40 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD*</td>
<td>General Population</td>
<td>P Value</td>
</tr>
<tr>
<td>Overall Health</td>
<td>90.9%</td>
<td>85.7%</td>
<td>0.25</td>
</tr>
<tr>
<td>Fair / Poor</td>
<td>19.1%</td>
<td>14.3%</td>
<td>0.25</td>
</tr>
<tr>
<td>Neurologic</td>
<td>11.2%</td>
<td>14.8%</td>
<td>0.002</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>9.8%</td>
<td>17.2%</td>
<td>0.002</td>
</tr>
<tr>
<td>Respiratory</td>
<td>19.8%</td>
<td>17.2%</td>
<td>0.54</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>23.3%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Celiac Disease</td>
<td>0.0%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Bowel Obstruction</td>
<td>0.0%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>16.4%</td>
<td>6.4%</td>
<td>0.007</td>
</tr>
<tr>
<td>Anxiety disorder</td>
<td>35.3%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>ADHD</td>
<td>27.6%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Schizophrenia or psychosis</td>
<td>3.5%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>7.8%</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Heart and Circulatory</td>
<td>12.9%</td>
<td>6.3%</td>
<td>0.05</td>
</tr>
<tr>
<td>Hypertension</td>
<td>9.5%</td>
<td>9.3%</td>
<td>0.05</td>
</tr>
<tr>
<td>Myocardial Infarction or Stroke</td>
<td>0.8%</td>
<td>0.4%</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Images from publically-available internet sites

Cardiovascular Complications of Obstructive Sleep Apnea (OSA))

complications of OSAC

• Hypertension (high blood pressure)
• Atherosclerosis (hardening of arteries)
• Heart attacks
• Heart failure
• Heart rhythm problems
• Stroke


Other complications of OSA

DAY

- excessive sleepiness
- afternoon drowsiness
- memory loss
- impaired concentration
- irritability
- headaches

NIGHT

- snoring and snorting
- observed apneas
- choking or gasping arousals, unexplained tachycardia
- restless sleep
- sweating during sleep
- nocturia
- bruxism
- nocturnal acid reflux

A negative test does not exclude clinically significant sleep apnea.

Tracings from Dr. Malow's lab
Sleep and Emotional Regulation

Sleep deprivation affects the neural circuitry underlying emotional regulation, including connectivity of the amygdala and prefrontal cortex.

- An fMRI study in which sleep-deprived healthy adults were compared with those who had slept showed increased amygdala activation after viewing images that were emotionally aversive.
- The functional connectivity was stronger between the medial-prefrontal cortex and the amygdala in the sleep control group, and the autonomic brainstem regions and the amygdala in the sleep-deprived group.

The human emotional brain without sleep—a prefrontal amygdala disconnect. Yoo et al., Curr Biol. 2007

Epilepsy “101”

- Epilepsy is defined as recurrent, unprovoked seizures.
- 20% to 30% of adults with autism have co-occurring epilepsy.
- Adults with autism and intellectual disability have higher rates of epilepsy than those with normal intelligence.
- Epilepsy can be missed if seizures are confused with behavioral tics, lack of responsiveness, emotional outbursts, or repetitive/stereotyped movements.
- Or overdiagnosed if these events are considered to be seizures.

Nicolaidis, 2014, Medical Clinics of N America
Epilepsy “101”

- Seizures can be missed more easily in patients with limited verbal skills.
- Caregiver education and capturing spells on video can aid accurate diagnosis.
- Consider seizure medications and drug interactions in differential diagnosis of a change in behavior.

Nicolaidis, 2014, Medical Clinics of N America
Nocturnal Seizures May Have:

- Bizarre clinical manifestations
- Preserved consciousness
- Rapid recovery
- No change in scalp EEG
- Observer may not be present, may be asleep, or may miss beginning of spell
- Aura and postictal period are masked by sleep
- BUT usually stereotyped in clinical presentation

*Sleep and Epilepsy. Sleep Disorders II. Neurologic Clinics,* Malow, 1996.