



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

Beange, McElduff, Baker; *Am J Ment Retard* 1995;99(6):595-604

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Rosa Marcellino
age 9

Rosa's Law
October 5, 2010

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)

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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

Key findings from Cooper et al.

- **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 | male | 76.4 years |
| female | <u>81.2 years</u> | female | <u>81.2 years</u> |
| | | | 78.8 years |

Lauer & McCallion. *J Appl Res Intellect Disabil.* 2015; 28:394-405

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

Charlot L et al. Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *J Intellect Disabil Res.* 2010;55(2):199-209

Health Disparities

Practitioners ID Medicine – Health Disparities

- 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

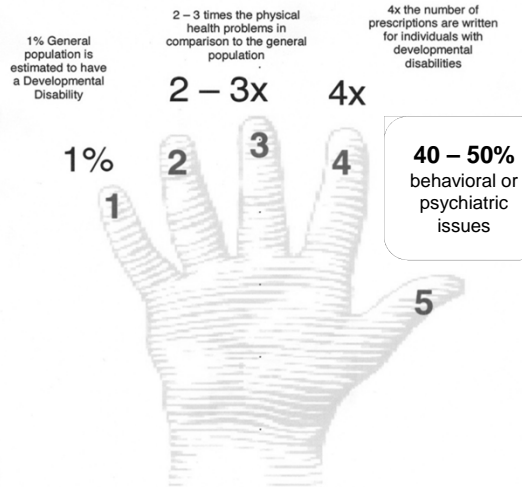
- **Physical**
 - transportation
 - accessible office
 - accessible exam room and table
 - non-ambulatory/non-weight bearing members
 - mammography equipment
 - mobility limitations due to spasticity or contractures

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?

Facts "On Hand" about Developmental Disability



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**?
10. How's the person **eating? / dental?** (added May 2012 to 2001 version)
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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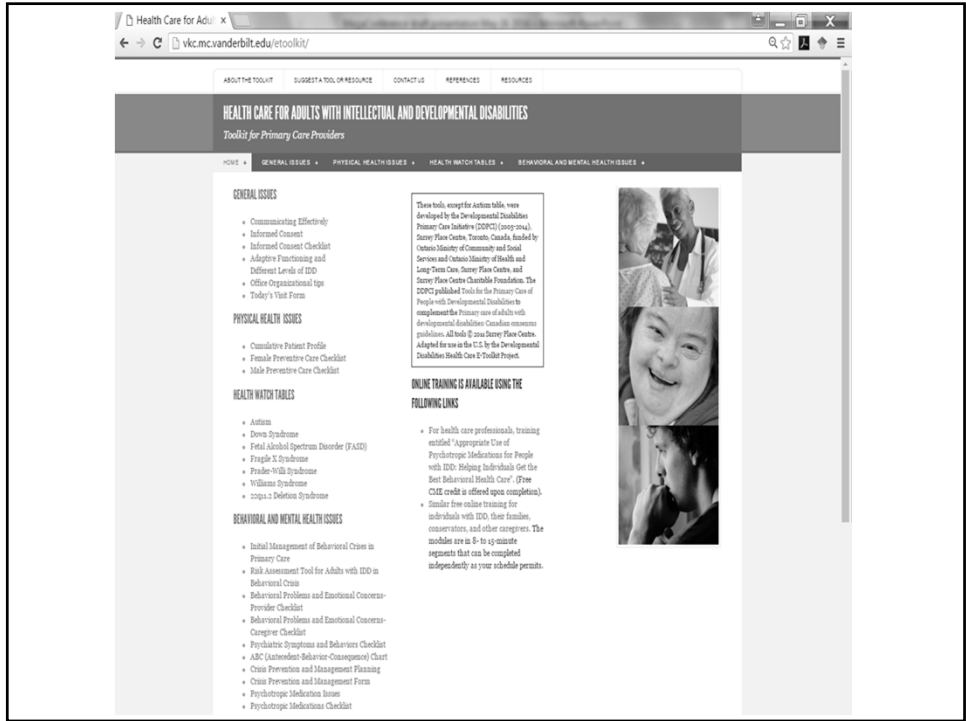
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www.tn.gov/didd

Click on Health Services: look under Video Learning

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Primary care of adults with developmental disabilities Canadian consensus guidelines

William F. Sullivan MD CCFP FRCPC Joseph M. Berg MD PhD MRCPsych FRCPC Elspeth Bradley MD MEds FRCPC FRCPC
Tom Cleechem MD CCFP Richard Denton MD CCFP FRCPC John Heng MD Brian Hennessy MD MEds CCFP
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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 participated in a colloquium and a subsequent working group discussed and revised the 2006 guidelines based on a comprehensive review of the literature, publications, feedback gained from users of the 2006 guidelines, and their own clinical experiences. Most of the available evidence was based on expert opinion or published case reports.

Main message Adults with DD have unique health issues that differ from those of the general population. The guidelines emphasize involving caregivers, when appropriate, and seeking input from a range of 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.

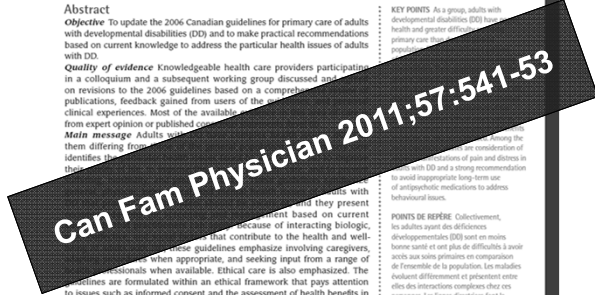
Qualité des preuves Des professionnels de la santé expérimentés participant à un colloque et un groupe de travail subséquent ont discuté et convenu des révisions aux lignes directrices de 2006 en se fondant sur une recherche documentaire exhaustive, la rétroaction obtenue des utilisateurs

KEY POINTS As a group, adults with developmental disabilities (DD) have unique health and general difficulties in their primary care that differ from those of the general population. The guidelines emphasize involving caregivers, when appropriate, and seeking input from a range of 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.

POINTS DE REPÈRE Collectivement, les adultes ayant des déficiences développementales (DD) ont en outre une santé et ont plus de difficultés à avoir accès aux soins primaires en comparaison de l'ensemble de la population. Les modules soulignent l'implication et le partenariat entre les intervenants complexes chez ces personnes. Les lignes directrices font la mise en jour des recommandations pour la santé générale, physique, comportementale et mentale des adultes ayant une DD, en particulier pour les problèmes qui ne sont pas réglés dans les évaluations symptomatiques de la santé dans la population en général. Elles traitent des questions d'éthique, comme le consentement éclairé et l'évaluation des bénéfices par rapport aux risques. Parmi les notes à jour les plus importantes, on peut mentionner les manifestations atypiques de douleur de la détresse chez les adultes ayant une DD et une très forte recommandation d'éviter l'utilisation à long terme inappropriée des antipsychotiques pour les problèmes comportementaux.

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.cfp.ca dans la table des matières du numéro de mai 2011 à la page e154.



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HEALTH CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Toolkit for Primary Care Providers

HOME | GENERAL ISSUES | PHYSICAL HEALTH ISSUES | HEALTH WATCH TABLES | BEHAVIORAL AND MENTAL HEALTH ISSUES

GENERAL ISSUES

- Communicating Effectively
- Informed Consent
- Informed Consent Checklist
- Adaptive Functioning and Different Levels of IDD
- Office Organization Tips
- Toolkit's User Forum

PHYSICAL HEALTH ISSUES

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

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

REFERENCES

These tools, except Action table, were developed by the Developmental Disabilities Primary Care Toolkit® (DDPCT) (2009-2010), Sunny Place Centre, Toronto, Canada, funded by Ontario/Ministry of Community and Social Services and Ontario/Ministry of Health and Long-Term Care, Sunny Place Centre, and Sunny Place Centre/ChildLife Foundation. The DDPCT 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 © 2009 Sunny Place Centre, All rights reserved. For more information on the Developmental Disabilities Health Care 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, caregivers, and other caregivers. The modules are 8- to 15-minute segments that can be completed independently as your schedule permits.



Name: _____

ASSESSMENT AND PLANS

Date: _____ Signature: _____

REFERENCES

DD references: Sullivan RT et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. Can Fam Physician 2011;57:140-53. Unless otherwise stated, recommendations come from the Canadian Task Force on Preventive Health Care: The Canadian Guide to Clinical Preventive Health Care. Ottawa: Minister of Supply and Services Canada; and www.vanderbilt.edu/etoolkit.

1. Scientific Advisory Board, Organization Society of Canada. 2010 Clinical practice guidelines for the diagnosis and management of intellectual disability in Canada. Summary. CMAJ 2010;182:1033-40, 1387-7.
2. Working Group on Intellectual Disabilities and Other Disabilities. Recommendations for the management and treatment of bipolar disorder and the prevention of comorbidity. Ottawa: 2008 update. Can Geriatr 2008;55(1):15-37.
3. Expert Working Group on Canadian Guidelines for DVA. Canadian Guidelines on Sexually Transmitted Infections, 2008 edition. Ottawa: Public Health Agency of Canada.

Original tool: © 2011 Sunny Place Centre. Developed by Heenan, B & Developmental Disabilities Primary Care Initiative Coauthors. Modified and reformatted with permission of Sunny Place Centre. • This tool was reviewed and adapted for U.S. use by physicians on the Toolkit's Advisory Committee. For full view: www.vanderbilt.edu/etoolkit

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RESOURCES

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Toolkit for Primary Care Providers

BEHAVIORAL AND MENTAL HEALTH ISSUES

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

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

- 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

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

Thank you!

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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)

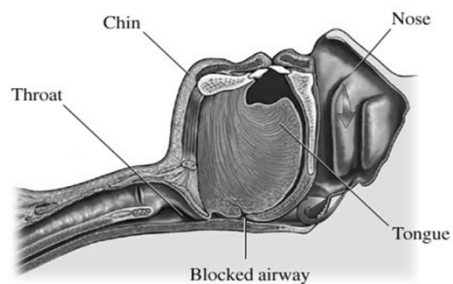
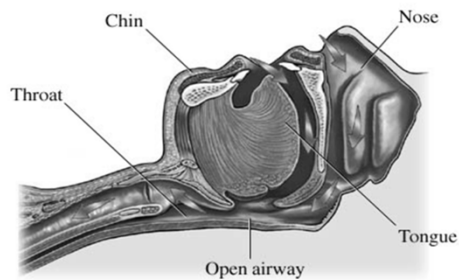
- What time is bedtime?
- How long does it take him to fall asleep?
- What time does he start waking up?
- What time does he wake up for good in the morning?
- Does he snore?
- What happens in his night wakings?
- Is he overweight? Obese?
- Family history of sleep disordered breathing?

Medical Conditions in Adults with Autism Spectrum Disorder (ASD)

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

Health Condition	18-29 years			30-39 years			> 40 years		
	ASD* (N=116)	General Population†	P Value	ASD* (N=67)	General Population†	P Value	ASD* (N=72)	General Population†	P Value
Overall Health									
Excellent / Good	80.9 %	85.7 %	0.25	68.7 %	86.1 %	0.004	82.9 %	80.2 %	0.59
Fair / Poor	19.1 %	14.3 %	0.25	31.3 %	13.9 %	0.004	17.1 %	20.0 %	0.56
Neurologic									
Seizure Disorder	11.2 %	1.4 % †	0.002	22.4 %	1.7 % †	<0.001	29.2 %	1.7 % †	<0.001
Migraine / Severe Headache	8.6 %	17.2 % †	0.004	4.5 %	20.5 % †	<0.001	0.0 %	15.1 % †	<0.001
Gastrointestinal									
Constipation	19.8 %	17.2 %	0.54	32.8 %	23.8 %	0.14	31.9 %	22.5 %	0.11
GERD	23.3 %	—	—	19.4 %	—	—	18.1 %	—	—
Celiac Disease	0.0 %	—	—	0.0 %	—	—	1.4 %	—	—
Bowel Obstruction	0.0 %	—	—	4.5 %	—	—	2.8 %	—	—
Psychiatric									
Depression	16.4 %	6.4 % §	0.007	17.9 %	6.7 % §	0.028	9.7 %	7.9 % §	0.65
Anxiety disorder	35.3 %	—	—	22.4 %	—	—	31.9 %	—	—
ADHD	27.6 %	—	—	9.0 %	—	—	2.8 %	—	—
Schizophrenia or psychosis	3.5 %	—	—	3.0 %	—	—	8.3 %	—	—
Bipolar disorder	7.8 %	—	—	3.0 %	—	—	4.2 %	—	—
Heart and Circulatory									
Hypertension	12.9 %	6.3 %	0.05	10.5 %	14.7 %	0.34	27.8 %	38.0 %	0.071
Hyperlipidemia	9.5 %	9.3 %	0.96	32.8 %	17.5 %	0.01	36.1 %	44.7 %	0.151
Myocardial Infarction or Stroke	0.0 %	0.4 %	0.009	0.0 %	0.8 %	<0.001	1.4 %	5.9 %	0.049

Health Conditions and Functional Status in Adults with Autism: A Cross-Sectional Evaluation; Fortuna et al., J Int Med, 2015



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

An update on cardiovascular effects of obstructive sleep apnoea syndrome. Uvar & Davutoglu, Postgrad Med J, 2016.

Other complications of OSA

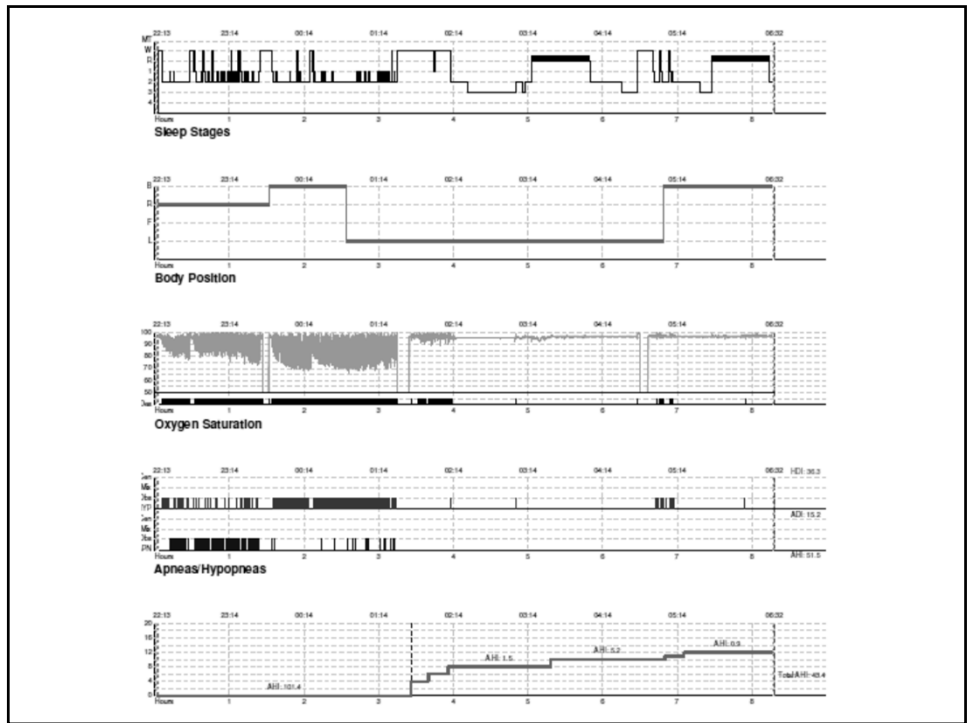
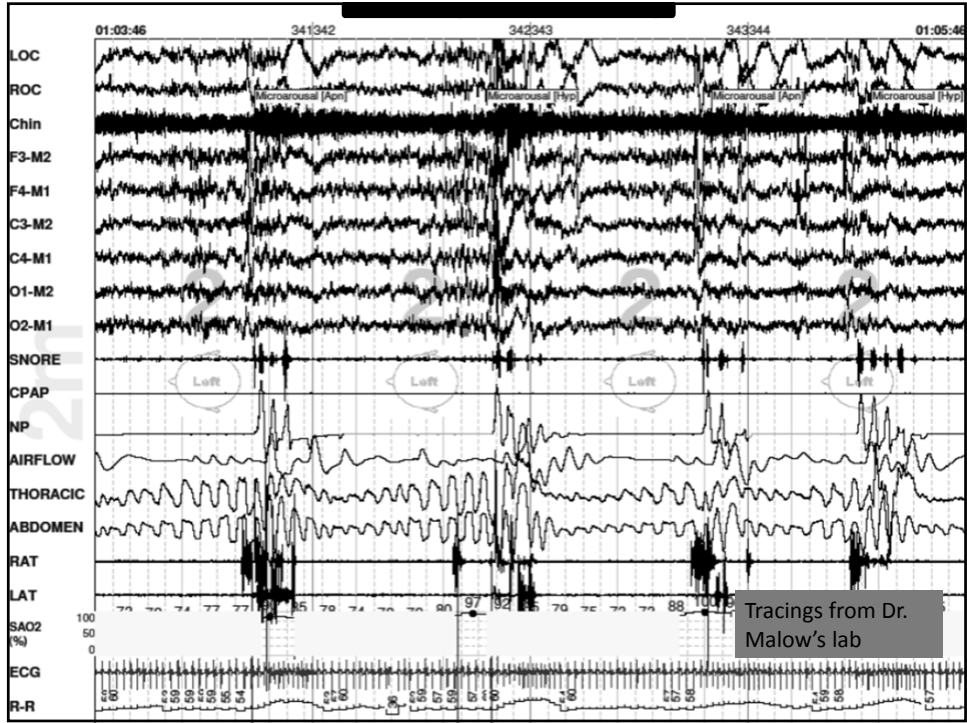
DAY

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

Sleep-disordered breathing.
Ioachimescu & Collop, Neurol Clin, 2012.

NIGHT

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

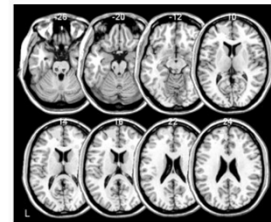
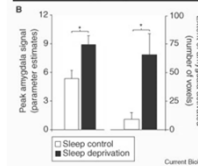


Sleep and Emotional Regulation

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



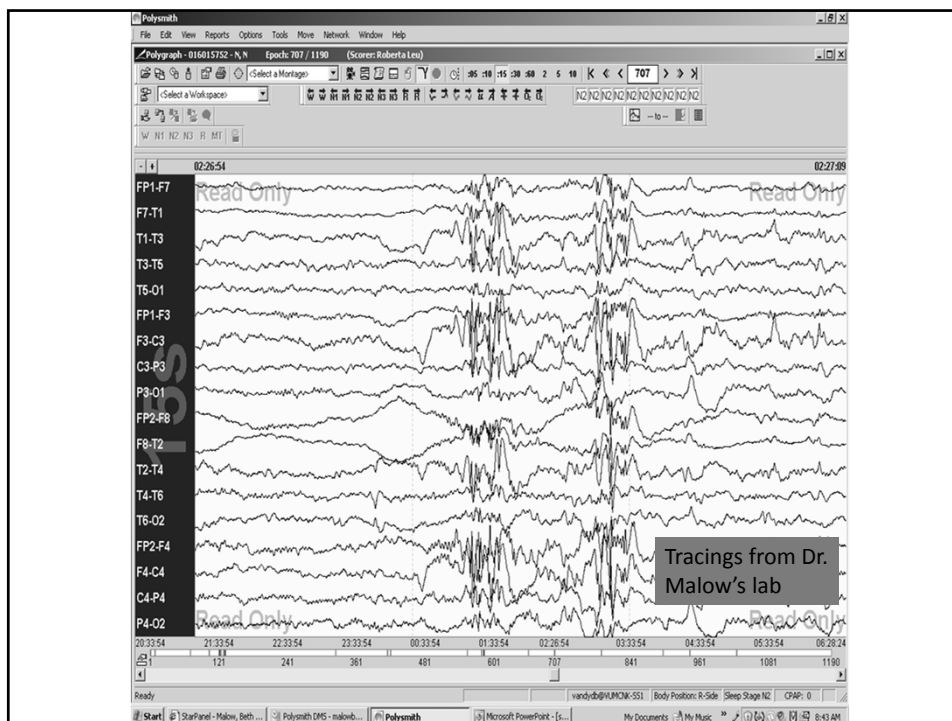
Epilepsy “101”

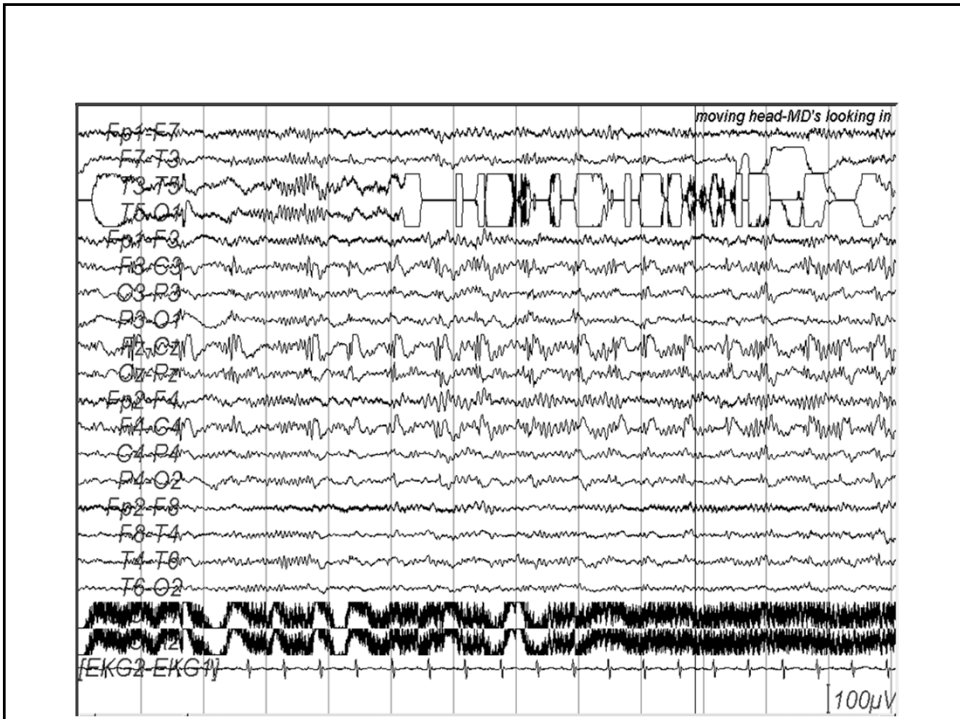
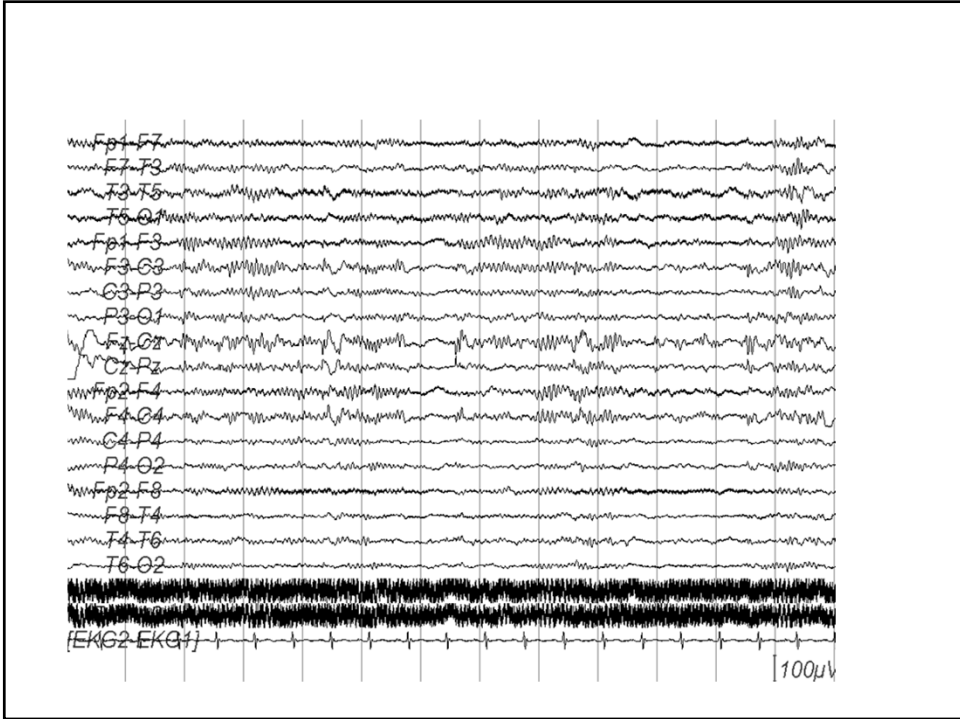
- Epilepsy is defined as recurrent, unprovoked seizures.
- 20% to 30% of adults with autism have co-occurring epilepsy.
- Adults with autism and intellectual disability have higher rates of epilepsy than those with normal intelligence.
- Epilepsy can be missed if seizures are confused with behavioral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

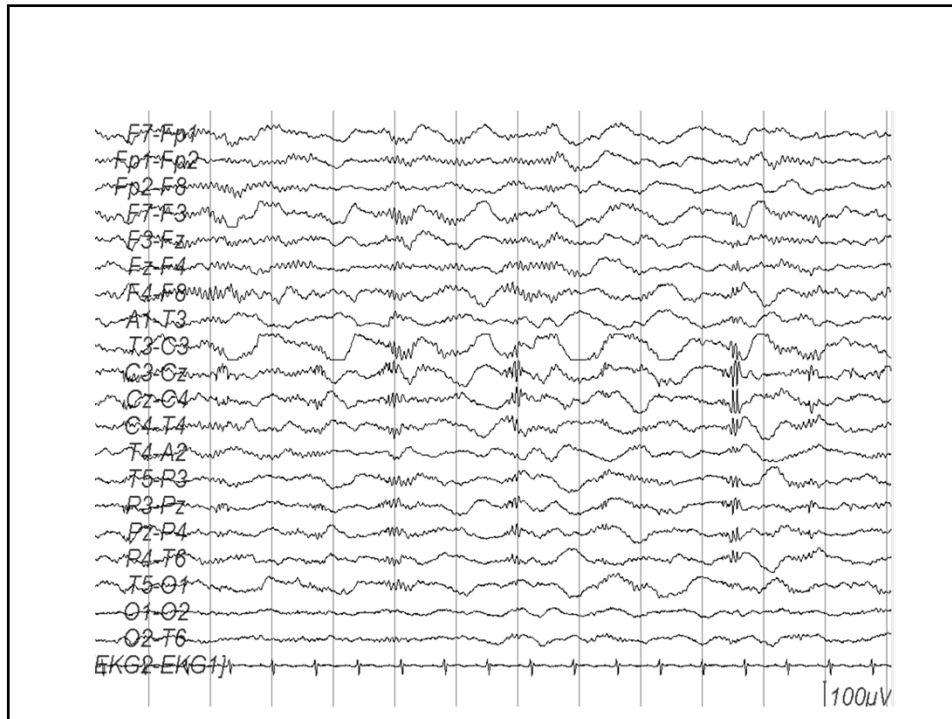
Epilepsy “101”

- 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.