



# ECHO I/DD

## Medical Co-Occurring Conditions in I/DD

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# Echo I/DD: Adult Healthcare Disclosures

- Target audience: those providing care for individuals with I/DD
- Objective: To improve the knowledge of primary care providers who care for adults with intellectual and developmental disabilities
- Speaker Disclosure: **Beth Malow** and **Mavara Agrawal** have no relationship with any commercial firm having products related to topics discussed at this conference. Actual disclosure forms are available upon request.

# Overview

- Sleep and I/DD
- Seizures
- GI and I/DD
  
- Highlight Resources  
(Autism Care Network  
and Vanderbilt Kennedy Center),  
CDC disease specific Growth  
curves

## Commonly Overlooked:

- Dental caries, periodontal disease
- Visual or hearing impairment
- Musculoskeletal conditions
- Anxiety, Depression, ADD/ADHD

# Sleep Problems

- Sleep problems are a common comorbidity in I/DD
- 50-80% of children with I/DD have sleep difficulties
- Sleep problems persist into the adult years
- Challenging daytime behaviors can be a result of sleep problems
- Parental stress is related to poor sleep in individuals with I/DD

# What is Insomnia?

- Trouble falling asleep (onset)
  - Trouble staying asleep (maintenance)
  - Early morning awakenings
  - Causes are usually multifactorial
    - Factors intrinsic to diagnosis/disability (over-arousal)
    - Medical and Psychiatric Conditions or Meds  
(ADHD with stimulants, depression with antidepressants, obstructive sleep apnea)
    - Habits (cell phones, caffeine, limited exercise)
- \*\* Habits can be more challenging for adults without a routine (not working, not in school)

# Ask and Assess

Every adult with I/DD should be screened for sleep problems routinely and especially if behaviors worsen

- Ask specific questions (let individual respond as able but also ask parent/caregiver)
  - How long does it take you to fall asleep?
  - When do you wake up in the morning?
  - What time does school/work start?
  - Do you wake up during the night? If so, how many times?
  - Does you snore?
  - Do your legs feel restless?

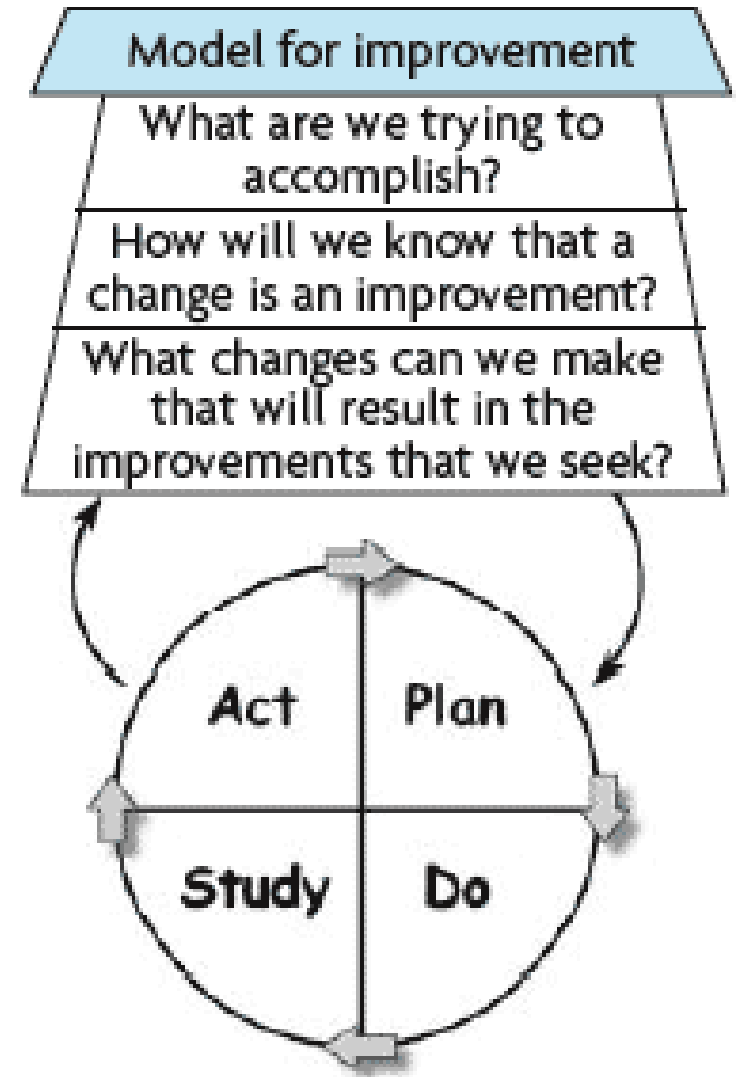
# Ask and Assess

- Gather Data

- Autism Care Network Sleep Log (see tool in Box)
- Family Inventory of Sleep Habits (see tool in Box)
- Activity Watch if available
- Assess for snoring, seizures, eczema, other medical conditions

# Address and Adjust

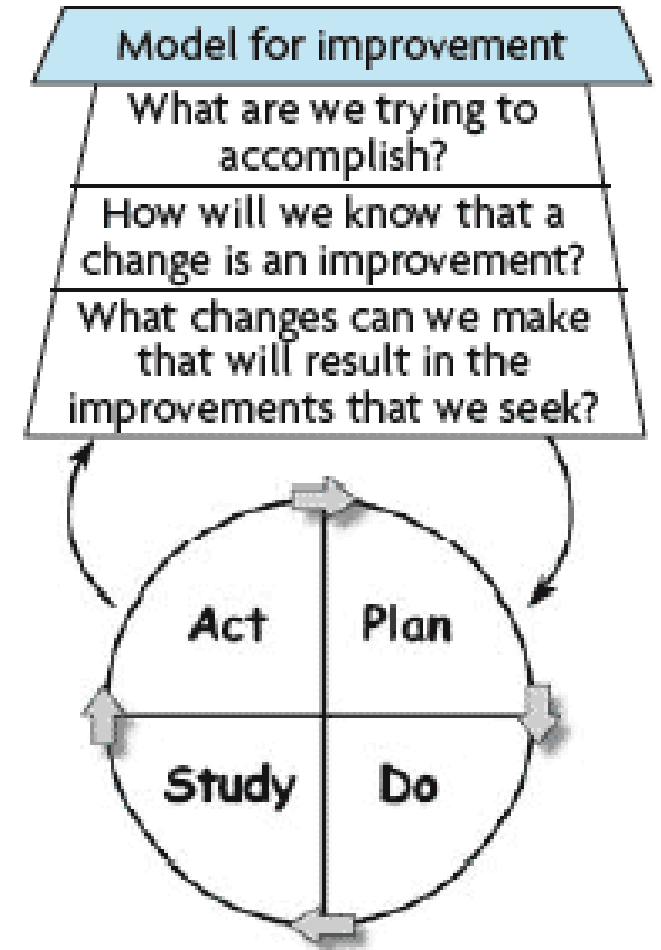
- Where to intervene?
  - Address underlying medical issues, consider sleep study for apnea or ferritin level for leg movements
  - Pay attention to daytime habits
    - Exercise, caffeine, devices
  - Select small areas family/adult can handle
  - Consider melatonin or sleep medication





# Address and Adjust

- Did the intervention work?
  - Gather data
  - Track improvement on sleep log or activity meter



# Seizures and I/DD

- Seizures are common in I/DD and persist into the adult years
- First seizure can occur in adult years
- Higher incidence of seizures in individuals with I/DD compared to typically developing peers
- Epilepsy is a cause of early premature death in I/DD

# Seizures and I/DD

- Seizures may affect sleep and daytime behavior and functioning
- Seizures take many forms ranging from full convulsions to staring spells with behavioral arrest
- Behavioral arrest and staring can be considered part of autism/I/DD so important to keep seizures in mind

# Ask and Assess

Every adult with I/DD should be screened for seizures routinely and especially if behaviors worsen

- Ask specific questions (let adult respond as able but also ask parent/caregiver)
- Have you ever had
  - Stiffening of muscles
  - Jerking of face, arms, or legs that you couldn't control
- Staring spells where person can't respond to voice or touch and "losing time" can also be seizures

# Ask and Assess

- Gather Data
  - Seizure diaries
  - EEG if suspect seizures
  - Review medical history for medications or other conditions that could contribute to seizures (head injury, etc.)

# Address and Adjust

- Most PCPs will refer to neurologist for treatment
  - You still have an important role to play in monitoring adult with I/DD and seizures
  - Discuss safety precautions (driving, exercise)
  - Ensure adult is taking medication regularly
  - Monitor for medication side effects (aggressions, osteoporosis)
  - Ensure proper sleep

# Address and Adjust

- Is the treatment working?
  - Gather data (seizure diaries, apps, etc.)

# Follow-up for All Conditions

- Follow-up to monitoring progress is essential
  - Ideally occurs 2 - 4 weeks after treatment begins
    - In person or by telephone
- Follow-up should include
  - Making appropriate adjustments to the intervention, if needed
  - Assess the support/ability for the family/adult to implement the intervention
  - Appropriate referrals to a specialist, if needed



# GI Conditions and I/DD

- GI conditions are common in I/DD and often persist into adulthood
- Higher incidence of constipation (30%), GER (40%), picky eating, diarrhea
- Discomfort from constipation or other GI symptoms may present as behavior or mood changes
- Contributors to GI symptoms in I/DD:
  - Anxiety
  - Sensory Processing
  - Limited food acceptance
  - Communication challenges

# Ask and Assess

Every adult with I/DD should be screened for GI conditions routinely, especially if behaviors worsen

- Ask specific questions (let patient respond as able but also ask parent/caregiver)
  - How is your appetite?
  - How often do you have a bowel movement?
  - Do you have pain or trouble passing stools?
  - Do you have loose stools (diarrhea)?
  - Do you have belly pain, heartburn, chest discomfort?

# Ask and Assess

- Gather Data
  - Follow weight with growth curves, esp. for specific medical condition
  - Dietary log (e.g., fiber and water intake)
  - KUB if suspect impaction
  - Consider CBC, calcium, glucose, thyroid studies, celiac panel, hypothyroidism, Crohn's disease

# Address and Adjust

- Where to intervene?
  - Address underlying medical issues (anxiety)
  - Pay attention to diet and daytime habits
    - Diet: if constipated, caution with fried foods and cheeses
    - Increase Fiber: apples, pineapple, blueberries, pears, mangos, peaches, spinach, eggplant, beans
    - Select small areas to work on: Fluids and physical activity
  - Consider use of probiotics and laxatives (Bisacodyl, MiraLAX, Mg)
  - Nutritional counseling, possible referral to GI specialist for endoscopy

# Address and Adjust

- Did the intervention work?
  - Gather data
  - Use of measured water bottle
  - Objective change in frequency of bowel movements, discomfort, improved sleep?

# Dental Conditions in I/DD

- Limited fine or gross motor skills, understanding, compliance,
- Hyper-sensitive, communication deficits, phobias
- Increased risk for caries, periodontal disease, bruxism, malocclusion
- Affects long term health and nutrition, esp. as they age

## Solutions:

Toothbrush timers and reminders, visual schedules, social stories, rewards, ABA, desensitizing, 360 degree

# Vision and Hearing Impairment in I/DD

- Hard to assess objectively due to challenges with communication or equipment or specialists
- Parent input and exam room observations (distance for viewing iPad/phone, gaze, volume, distance from objects of interest)
- Referral to specialists

# Musculoskeletal Disorders in I/DD

- Increased risk for fractures and osteoporosis due to medications and limited nutrition may be missed
- Scoliosis, hip dysplasia, spasticity and contractures, joint instability, sprains and strains
- Limited information, communication, sensitivities

Parent Input and Exam room observations: inability to use limb, comparison to other limb, limited motions, decrease in favorite activities

Assessment: exam and studies, referral to PT/OT and specialists



# Resources



## Preparing adults with I/DD for a sleep study

<https://vkc.vumc.org/assets/files/resources/sleepstudy-adults.pdf>

A screenshot of the website 'HEALTH CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES Toolkit for Primary Care Providers'. The page has a blue header and a navigation menu with categories: HOME, GENERAL ISSUES, PHYSICAL HEALTH ISSUES, HEALTH WATCH TABLES, and BEHAVIORAL AND MENTAL HEALTH ISSUES. The main content area is divided into four sections: GENERAL ISSUES (with links like 'Communicating Effectively'), PHYSICAL HEALTH ISSUES (with links like 'Cumulative Patient Profile'), HEALTH WATCH TABLES (with links like 'Autism'), and BEHAVIORAL AND MENTAL HEALTH ISSUES (with links like 'Initial Management of Behavioral Crises'). A central text box explains that the tools were developed by the Developmental Disabilities Primary Care Initiative (DDPCI) and adapted for use in the U.S. by the Developmental Disabilities Health Care E-Toolkit Project. On the right side, there are three small images: a doctor with a patient, a smiling woman, and a young person.

[www.iddtoolkit.org](http://www.iddtoolkit.org)

Growth charts: [CDC Growth Charts for Genetic DO](#)



**ECHO I/DD**

Thank you!