

Eden Autism Services
March 7, 2019

Clinical Awareness in IDD Healthcare

▶ PRESENTED BY:
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About the Presenter:

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- ▶ Board-Certified Fellow of the American Academy of Family Physicians
- ▶ Over 20 years of experience caring for people with mental illness and intellectual and developmental disabilities
- ▶ Medical Director of Hudspeth Regional Center in Whitfield, MS – Retired 2018
- ▶ Founder and Clinical Director of DETECT
- ▶ President of HRS, Inc.



My Journey

- ▶ Upbringing
- ▶ Introduction of new ideas
- ▶ Questioning
- ▶ Doubting
- ▶ Learning
- ▶ Experiencing
- ▶ New views
- ▶ Teaching
- ▶ Creating the new norm



QUESTIONS

- ▶ What are the top preventable causes of death in people with IDD?
- ▶ How can you distinguish between medical and mental conditions in people with IDD?
- ▶ How can you facilitate the best healthcare visit for people with IDD?

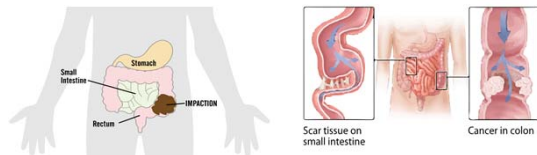


WHAT ARE THE TOP PREVENTABLE CAUSES OF DEATH IN PEOPLE WITH IDD?



Bowel Obstruction

Blocking of movement through the GI tract from scar tissue, lack of movement (peristalsis) or constipation or foreign body



Bowel Obstruction

- ▶ Major cause of death in the community
- ▶ Inability to communicate pain or other symptoms
- ▶ Over-reliance on bowel management medications
- ▶ Influence of anti-cholinergic drugs
- ▶ Failure to implement early intervention
- ▶ Risk of repeat incidents is VERY high!



The GI Tract

It is impacted by...EVERYTHING

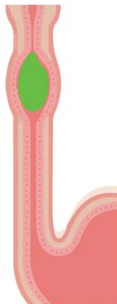
- ▶ Medications
- ▶ Stress
- ▶ Physiology
- ▶ Position
- ▶ Nutrition/hydration



Peristalsis

Primary peristaltic wave: Esophagus

- ▶ Stomach stores food, mixes it up with digestive juices and empties contents slowly into the small intestine
- ▶ Finally, all digested nutrients absorbed through intestinal walls
- ▶ Undigested products propelled into colon, and remain for a day or two, until expelled as a bowel movement.



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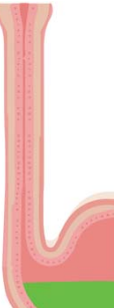
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Constipation

Primary cause of "everything"

- ▶ Fever
- ▶ Anorexia
- ▶ Vomiting
- ▶ Seizures
- ▶ Medication Intoxication
- ▶ Decreased LOC
- ▶ Pneumonia
- ▶ Behavioral outbursts
- ▶ Death



Constipation - Causes

- ▶ Decreased GI motility
- ▶ Immobility
- ▶ Lack of sensation
- ▶ Diet
- ▶ Medications
 - ▶ Anti-Epileptic Drugs
 - ▶ Antipsychotics
 - ▶ Iron
 - ▶ Anti-cholinergics
 - ▶ Opiates
- ▶ Pica
 - ▶ Common
 - ▶ May cause bowel obstruction



Constipation - Treatment

- ▶ Diet
 - ▶ Fiber
 - ▶ Adequate fluid intake
- ▶ Laxatives
 - ▶ MOM
 - ▶ Mg Citrate
 - ▶ Polyethylene glycol
- ▶ Suppositories
- ▶ Enemas
- ▶ Manual dis-impaction



Dietary Issues

- ▶ Not enough fiber
- ▶ Not enough fluid
- ▶ Not enough movement

For high fiber recipes see the "handout" section of the control panel



Prevention

1. Avoid use of irritant laxatives
2. Provide adequate fluid - 8 oz. for every 6-7 g a day
3. Increase dietary fiber gradually - 6-8 g every 2 weeks
4. Give time and attention to periods of high gut motility
5. Increase physical activity
6. Supplement gut flora with yogurt, or pro-biotics with 6 to7 billion organisms per capsule
7. Uncooked, high-fiber fruits and vegetables at each meal



Aspiration

Breathing food or fluid into the airway

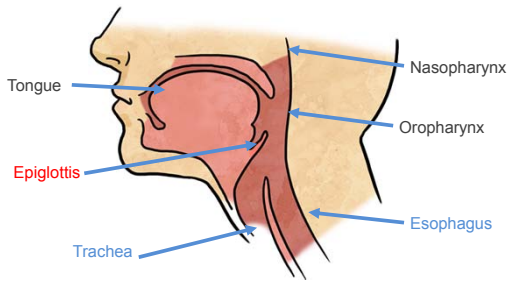


Aspiration

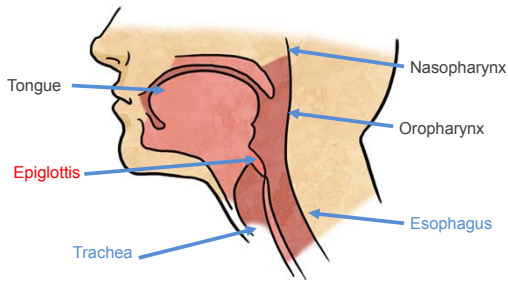
- ▶ A high cause of death in people with IDD
- ▶ Influenced by many factors
- ▶ Individual management and staff training are critical!
- ▶ Identifying root cause is vital!
- ▶ Can be caused by food going in or out of the stomach



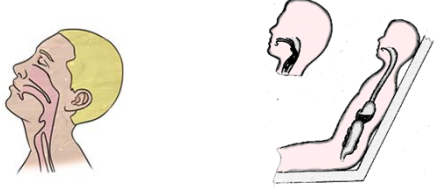
Anatomy of the Head and Neck



Anatomy of the Head and Neck




Aspiration in Sitting





Aspiration in hyperextension

Aspiration during intake due to poor tongue mobility and positioning in reclined sitting





Aspiration

- ▶ Acute
- ▶ Large quantity of aspirated material
 - ▶ Can result in death
- ▶ Smaller quantity
 - ▶ Pneumonia
- ▶ Recurrent
 - ▶ Frequent pneumonia
 - ▶ Wheezing



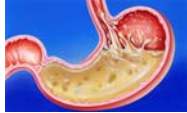
Aspiration – Subtle Signs and Symptoms

- ▶ Cough - especially with feeding
- ▶ Refusal to drink thin liquids
- ▶ Resistance in eating or drinking
- ▶ Recurrent pneumonia
- ▶ Reactive airway disease



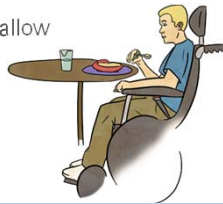
Aspiration - Causes

- ▶ Constipation
- ▶ GERD
 - ▶ Reclined positioning
 - ▶ Liquid diet
- ▶ Dysphagia
- ▶ GI dysmotility
- ▶ Sedation
 - ▶ Medications
 - ▶ Illness



Aspiration - Prevention

- ▶ Positioning
- ▶ Feeding techniques
 - ▶ Feeding evaluation
 - ▶ Thickening Liquids
 - ▶ Food texture/size
- ▶ Test - Modified barium swallow
- ▶ PEG Tube
 - ▶ Volume/Time
- ▶ J-Tube
- ▶ J-Tube/PEG

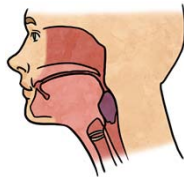


Getting in trouble with swallowing

Aspiration is about swallowing only 25% of the time!

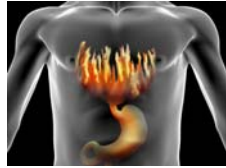
Look at the following

- ▶ Before it goes down?
- ▶ As it goes down?
- ▶ Does it go down?
- ▶ Does it get out of the stomach?
- ▶ Does it come out the other end?



Gastroesophageal Reflux disease (GERD)

Back flow of partially digested food and acid into the esophagus causing pain and inflammation



Gastroesophageal Reflux disease (GERD)

Multiple causes of death

- ▶ Massive GI bleed
- ▶ Esophageal cancer
- ▶ Aspiration of stomach contents



Common Signs Not Recognized

- ▶ Pica
- ▶ Hands in mouth
- ▶ Agitation within 30 minutes of eating
- ▶ Refusing meals
- ▶ Agitation and restlessness in the middle of the night
- ▶ Clinical signs: eroding hemoglobin, hematocrit and albumin (blood protein)
- ▶ Unplanned weight loss regardless of intake



Diagnosis

- ▶ PH monitor
- ▶ Barium Swallow
- ▶ Endoscopy
- ▶ Oxygen Saturation decreasing at any time during or after mealtime

MEALTIME PULSE OXYMETER STUDY GENERAL GUIDELINES

- BASELINE**
S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- MEALTIME RANGE**
S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- LENGTH OF MEALTIME**
S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- COUGHING EPISODES**
Coughing or choking during a mealtime and its effect on S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- COUGHING WITH COLOR CHANGES**
Coughing with color changes during a mealtime and its effect on S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- RECOVERY OF S_{at}O₂ AND PULSE**
S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- OXYGEN SATURATION**
S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.
- INAPPROPRIATE S_{at}O₂ DURING MEALTIMES**
S_{at}O₂ and pulse normally outside of eating. This is best done for one week prior to the mealtime.

MEALTIME PULSE OXYMETER STUDY GENERAL GUIDELINES

Name: Jan Jones Date: 2/2/19
 Assessed by: K. Owen, RSI

Start Date: 12:00pm Report Interval: 30s Limit: 98 Avg: 94-99
 Baseline: 95% Pulse: 90 Percent of Baseline: 0 0 0
 Mealtime Range: 94-98 Pulse: 85-100
 Length of Mealtime: 22 min
 Cough/Choking: 3
 Single Color: 0
 Cough with Color Change: 0
 Duration of S_{at}O₂ Data: None None
 How Often: None
 S_{at}O₂: 92 for 2 min
 S_{at}O₂: 94 for 15 min
 S_{at}O₂: 92 when None

3) Normal (fluctuates in S_{at}O₂/pulse) during mealtime.
 4) S_{at}O₂/pulse normally changes from 92-98/pulse normally changes from 85-100.
 5) There were single coughs and 30 seconds post-meal period. S_{at}O₂ and pulse not significantly affected.
 6) No "low" oxygenation noted during or after the meal.
 7) No color changes in skin during or after the meal.

Seizures

An alteration in brain function resulting in changes in awareness, or function for a brief period of time



Seizures

- ▶ Can be most severe and difficult to treat
- ▶ Varying presentations
- ▶ Status epilepticus prevalent
 - ▶ Sub-clinical status - rapid eye movements
- ▶ Accurate seizure record VERY helpful in management



SEIZURE RECORD												
Name: _____											Case# _____	
Date	Time	How Long?	Start/End	Where?	Activity?	After Activity	Reason	EEG	Notes	Signature/Title		
		Y N	Y N	L R B	Trac	H/A	S/nc	Y N	Y N			



Seizures

Status epilepticus

- ▶ Respiratory suppression
- ▶ SUDEP - Sudden Unexplained Death in Epilepsy



Seizures – Precipitating Factors

- ▶ Constipation
- ▶ Infection
- ▶ Medication compliance issues
- ▶ Menses
- ▶ Age
- ▶ Shunt issues
 - ▶ May see change in LOC
- ▶ Head Injury
- ▶ Stroke
- ▶ Hypoglycemia
- ▶ Electrolyte Imbalance



Seizures

Drug toxicity

AED's – always one of the top 10 most dangerous drugs



Seizures

Seizure sequelae

- ▶ Aspiration
- ▶ Accidents



Seizures – What to do

- ▶ Ease the person to the floor.
- ▶ Turn the person gently onto one side. This will help the person breathe.
- ▶ Clear the area around the person of anything hard or sharp. This can prevent injury.
- ▶ Put something soft and flat, like a folded jacket, under his or her head.
- ▶ Remove eyeglasses.
- ▶ Loosen ties or anything around the neck that may make it hard to breathe.
- ▶ Time the seizure. Call 911 if the seizure lasts longer than 5 minutes. Follow your program's guidelines.



Audience Question...

Would you say that you have a basic understanding of what "Sepsis" is?

- ▶ Yes
- ▶ No



Sepsis

Blood poisoning due to failure of the immune system to respond to infection.



Sepsis

- ▶ Also known as Blood Poisoning
- ▶ Caused by an infection or its toxin spreading through the bloodstream
- ▶ Occurs when large numbers of infections agents invade the bloodstream leading to bacteremia
- ▶ Initial infection often comes from:
 - ▶ Burn, ulcer or open wound
 - ▶ Pneumonia
 - ▶ Urinary Tract Infection (UTI)



Sepsis is a Silent Killer

- ▶ A "silent killer" whose early diagnosis could save thousands of lives each year
- ▶ Should be treated aggressively
- ▶ Very prevalent, costly disease with a high in-hospital mortality rate



Sepsis Signs and Symptoms

- ▶ High temperature
- ▶ Rapid pulse
- ▶ Chills
- ▶ Low blood pressure
- ▶ Mottling of the skin
- ▶ Confusion and lightheadedness



Audience Question...

Have you ever lost a person that you support or in your family from sepsis?

- ▶ Yes
- ▶ No



Every hour that passes without treatment raises death risk by 10%

When in doubt, send them out!



Dehydration

- ▶ Vomiting
- ▶ Limited intake
 - ▶ Limited ability to communicate thirst
 - ▶ Immobility to access fluids
 - ▶ Loss during intake
 - ▶ Medical conditions – DM
 - ▶ Staff awareness
- ▶ Dysphagia
- ▶ Drooling
- ▶ If PEG Tube – inadequate amount of fluids provided
- ▶ Draining PEG- Excess fluid loss without replacement
 - ▶ Follow electrolytes



Recap

- ▶ Bowel Obstruction
- ▶ Aspiration
- ▶ GERD
- ▶ Seizures
- ▶ Sepsis
- ▶ + Dehydration

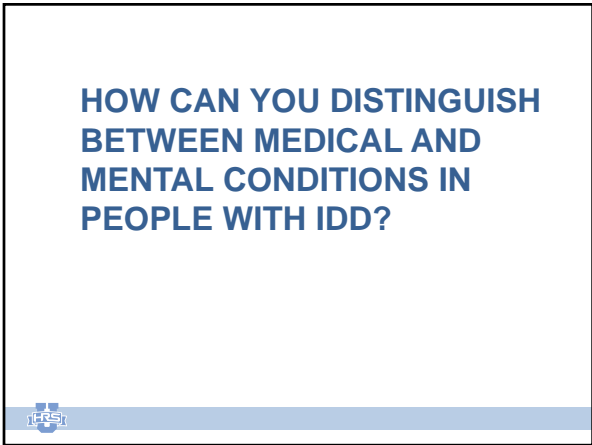


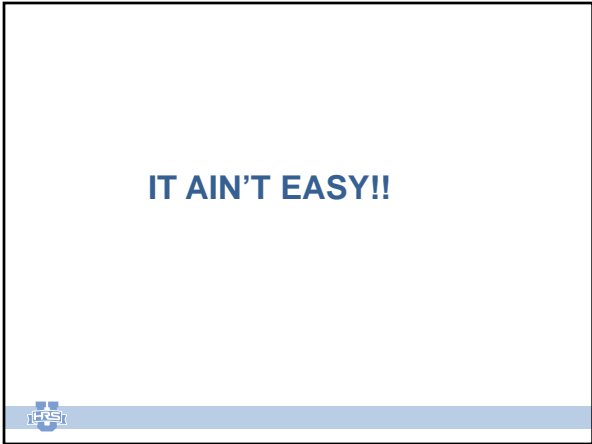
Remember...

When in doubt, send them out!









Dual Diagnosis

- ▶ Two conditions that occur together
 - ▶ IDD
 - ▶ Mental Health Issue
 - ▶ Substance use issues
- ▶ Co-existence of the symptoms of both **intellectual or developmental disabilities and mental health problems**



Prevalence of Dual Diagnosis

- ▶ Estimated that 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder
- ▶ Estimated 2/3 of people with IDD are on a psychotropic medication.
- ▶ Treating behavior with psychotropic medications



IDD

- ▶ Usually born with it
- ▶ Evidence of it from an early age
- ▶ Doesn't get better
- ▶ Impacts all areas of functioning
 - ▶ Communication skills
 - ▶ Social interaction
 - ▶ Activities of daily living



How is IDD Diagnosed?

- ▶ Standardized tests such as an **IQ test** are used to determine a child's level of intellectual development.
- ▶ A score **below 70** on a standardized IQ test indicates that he may have intellectual development disorder.
- ▶ One must also exhibit **deficiencies in two or more specific areas of adaptive behavior**, such as communication skills, interpersonal skills, or daily living skills like getting dressed and using the bathroom.



How are Mental Illnesses Diagnosed in People Without IDD

- ▶ Evaluation of symptoms expressed during an interview
- ▶ Evaluation of social and functional problems
- ▶ Lab testing
- ▶ Diagnostic testing
 - ▶ Patient Health Questionnaire-9
 - ▶ Beck Depression Inventory
 - ▶ Generalized Anxiety Disorder-7
 - ▶ CAGE test for substance abuse
- ▶ DSM-5 Criteria



STATEMENT

Diagnosing Mental Illness in People with IDD is Complicated



Evaluation by Observation

- ▶ Eating sleeping and activities
- ▶ Assess current environment
- ▶ Activities
- ▶ Expectations by others
- ▶ Changes in living situations
- ▶ Gains made by certain actions
- ▶ Look at behaviors
- ▶ What triggers the behaviors
- ▶ What stops the behaviors



Go to the Experts

Involving direct caregivers in plan development

- ▶ Staff often work closest to and spend most time with people
- ▶ Encourage contributions, observations, hypotheses, ideas, intervention strategies
- ▶ Staff can identify trends and missing puzzle pieces that managers and behaviorists often cannot
- ▶ Foster control and confidence
- ▶ Promote participation and involvement in planning
- ▶ Consider opinions and answer questions
- ▶ Provide ongoing support and guidance



Best Practice Assessment: Bio-psycho-social Model

1. Review Reports
2. Interview Family
3. Interview Care Provider
4. Direct Observation
5. Clinical Interview



Behavior and Medical Issues

MUST ASSESS FOR MEDICAL PROBLEMS

- ▶ Downs
 - ▶ Thyroid Disease-Depression
 - ▶ Dementia
- ▶ Pain may result in challenging behaviors
- ▶ GERD can cause agitation and/or confusion
- ▶ Patterns to behavior? - PMS



Behaviors Associated with GI Distress/Reflux

- ▶ Hand mouthing
- ▶ Pica
- ▶ Food refusal
- ▶ Coughing when lying down
- ▶ Physical or verbal aggression particularly around meal times



Behaviors Associated with Head Pain

- ▶ Head banging
- ▶ Head butting
- ▶ Hitting or slapping self
- ▶ Inserting objects into ears or nose
- ▶ Crying
- ▶ Withdrawal from areas with light or noise
- ▶ Sitting with head in lap
- ▶ "Refusals" to listen or respond (loss or reduction in hearing)
- ▶ Hands over ears or face
- ▶ Tilting head to one side



Behaviors Associated with Medication Side Effects

- ▶ Blinking
- ▶ Medication refusal
- ▶ Refusal to eat
- ▶ Urinary or fecal incontinence
- ▶ Constipation
- ▶ Urinary retention
- ▶ Aggression
- ▶ Fatigue
- ▶ Weight gain or loss
- ▶ Agitation
- ▶ Scratching self
- ▶ Falls, change in cognitive status
- ▶ Tics, dystonic symptoms
- ▶ Muscle twitching



Behaviors associated with Pneumonia

- ▶ Fatigue
- ▶ Withdrawal
- ▶ Refusal to eat
- ▶ Falls
- ▶ Increased irritability
- ▶ Change in cognitive status
- ▶ Refusal to lie down to sleep



Behaviors Associated with Dental Issues

- ▶ Hitting self
- ▶ Hands in mouth
- ▶ Refusal to eat
- ▶ Spitting out food
- ▶ Physical or verbal aggression particularly around meal times



Behaviors Associated with Constipation

- ▶ Guarding abdomen
- ▶ Rocking
- ▶ Not able to sit still (up and down)
- ▶ Hitting self in abdomen
- ▶ Fetal position when lying
- ▶ Knees drawn up to chest when sitting
- ▶ Physical or verbal aggression without definite antecedent
- ▶ Refusal to eat



Behaviors associated with Seizures

- ▶ Disrobing
- ▶ Increased agitation
- ▶ Failure to "pay attention" in children or "daydreaming"
- ▶ Sexually acting out
- ▶ Physical or verbal aggression with no trigger
- ▶ Repetitive or ritualistic type behaviors that are short lived
- ▶ Rapid eye blinking
- ▶ Tantrums
- ▶ Falls
- ▶ sudden "sleep"
- ▶ random talking
- ▶ hard to "reach"



Behaviors Associated with Urinary Tract Infections

- ▶ New onset urinary incontinence
- ▶ Agitation
- ▶ Not able to sit still (up and down)
- ▶ Repetitive trips to toilet
- ▶ Screaming when approaching toilet or with incontinence
- ▶ Grabbing genitals or rubbing with objects
- ▶ Hands in pants
- ▶ Physical or verbal aggression with no trigger
- ▶ Abdominal guarding
- ▶ Rocking
- ▶ Change in cognitive status
- ▶ Fatigue



Behaviors associated with Chest pain

- ▶ Scratching, hitting or rubbing chest
- ▶ Crying
- ▶ yelling out
- ▶ Agitation
- ▶ Anxiety
- ▶ Shortness of breath
- ▶ Weakness



Behavior

- ▶ Consider Behavior as a form of communication
- ▶ Need to understand the context of the behavior
- ▶ When does it happen and when does it not
 - ▶ Helps identify what's being communicated
- ▶ Are our expectations out of line
 - ▶ "They are not nice"
 - ▶ "They won't do what I want them to do"



Behavior has a Function

Behaviors may persist because the person...

- ▶ Enjoys the sensory experience – it feels better, satisfies a need or impulse (internal triggers, internal rewards)
- ▶ Escapes or avoids demands or things he or she doesn't like to do
- ▶ Gains attention from others
- ▶ Obtains tangible items or opportunities – access to something he or she prefers

Beavers, Iwata, & Lerman, 2013



Indications that a behavioral pattern may be the result of a psychiatric condition

- 1. The behavior occurs in all environments; it is not just exhibited in specific settings
- 2. Behavioral strategies have been largely ineffective
- 3. The person in service doesn't appear to have control over their behavior. He/she doesn't appear to be able to start or stop the behavior at will.

Adapted from McGilvery & Sweetland, 2011



Indications that a behavioral pattern may be the result of a psychiatric condition

- 4. There are changes in sleep patterns; increased, decreased or disturbed sleep.
- 5. The person in service is experiencing excessive mood or unusual mood patterns.
- 6. There are changes in the person's appearance and a decline in their independent living skills.

Adapted from McGilvery & Sweetland, 2011



Indications that a behavioral pattern may be the result of a psychiatric condition

- 7. The person may start to engage in purposeful self-harm (cutting, hitting, scratching, pulling out hair).
- 8. The person may start to show signs of hallucination, such as staring to the side or corners and not appear to track conversations.
- 9. There may be changes in eating patterns such as eating less or more.

Adapted from McGilvery & Sweetland, 2012



Indications that a behavioral pattern may be the result of a psychiatric condition

- 10. The person in service has a history of a psychiatric disorder that was in remission.
- 11. There is an acute onset of the behavior. If there is a particularly rapid onset with a significant change in mental status or cognitive functioning, rule out a possible delirium with an underlying medical cause.
- 12. There is an unusual change in behavior patterns, such as a significant change from baseline behavior

Adapted from McIlhenny & Sweetland, 2012



Medical Problems may cause significant alterations in mood and behavior that mimic acute psychiatric illness.



Charlot et al., 2011




Mental or Medical?

- | | |
|---|---|
| ▶ MANIA
Irritable, restless, pacing, running back and forth, can't sit still, can't focus, can't get to sleep | ▶ AKATHISIA
Irritable, restless, pacing, running back and forth, can't sit still, can't focus, can't get to sleep |
| ▶ DEPRESSION
Crying, won't get out of bed, decreased concentration | ▶ CONSTIPATION
Crying, won't get out of bed, decreased concentration |

Charlot et al., 2011



HOW CAN YOU FACILITATE THE BEST HEALTHCARE VISIT FOR PEOPLE WITH IDD?



GOOD COMMUNICATION IS THE FOUNDATION FOR GOOD OUTCOMES



Challenges to Good Communication

- ▶ Physicians have been placed in a position where they have numerous conflicting task priorities when they go in to see patients
- ▶ Doctors must account for every statement, question and answer in an electronic health record with more than 100 measures, patterns and health outcomes being tracked by national organizations.
- ▶ Result- face-to-face time with patients has dropped



Challenges to Good Communication

- ▶ Healthcare providers likely have received little training in the field of IDD medical care.
- ▶ People who take patients to appointments may not have a good working understanding of medical issues
- ▶ There is a language barrier between people with IDD, their caregivers and the healthcare providers



What can YOU do to improve communication?

- ▶ Be prepared for the appointment
 - ▶ Know your patient's baseline
 - ▶ Clear, simple description of what the primary issue is
 - ▶ Prioritize concerns if there are multiple issues
 - ▶ Have any supporting documents available
 - ▶ Seizure record
 - ▶ Glucose record
 - ▶ Behavior Reports
 - ▶ BM report
 - ▶ Updates since last visit
 - ▶ Medications
- ▶ Let the office staff know what the appointment is for and if there is a need for extended time to accomplish goals



What can you do to improve communication?

- ▶ Gain an understanding of general medical terminology
- ▶ Learn what information will help healthcare providers the most and have it readily available
- ▶ Sharpen your skills in recognizing medical issues in people you support

This will not only improve communication but also improve the health of those you support!



What can you do to improve communication?

- ▶ Know the baseline of the patient
- ▶ Have a brief summary of the persons medical history
- ▶ Talk to other members of the team for their input
- ▶ Know if the patient has been compliant with medication and treatments
- ▶ Ask questions about what you don't understand
- ▶ Take notes
- ▶ Get written materials
- ▶ Have contact information for nurse or other team members available



What information do clinicians want to know?

- ▶ What is the patient's baseline
- ▶ What changes have been noticed
- ▶ How long has it been going on
- ▶ How often does it occur
- ▶ What makes it start/stop
- ▶ What has been tried



Before, During and After the Visit



Before the Visit

- ▶ Take a list of specific questions to the appointment, making sure to list the most important ones first.
- ▶ Familiarize yourself with the person's medical history, so you can convey it concisely to your doctor. Writing out a brief synopsis to give a new doctor can be helpful and save time.
- ▶ Keep a diary to track symptoms and concerns. Convey these clearly to the doctor.
- ▶ List medications they are taking with their dosages. Tell the doctor about any medication changes.



During the Visit

- ▶ Communicate the type of home environment that the person lives in.
- ▶ Tell the provider that you are here to support the person and to direct questions to the person if possible.
- ▶ Don't let the person get separated from their communication device if possible.
- ▶ Tell the clinician how the person's issues impact their life.
- ▶ Ask for clarification if you don't understand what you have been told or if you still have questions.



During the Visit

- ▶ Ask for explanations of treatment goals and side effects.
- ▶ Bring a pencil and notebook to take notes
- ▶ Let your doctor know if the person is seeing other doctors or health care providers.
- ▶ Share information about any recent medical tests or other visits.
- ▶ Be an advocate the person.
- ▶ Balance assertiveness with friendliness and understanding



After the Visit

Review all information with the patient and the team after the visit.



Communicating a Person's Baseline



Determining Someone's Baseline

- ▶ Mobility
- ▶ ADLs
- ▶ Nutrition
- ▶ Toileting
- ▶ Social
- ▶ Behavioral
- ▶ Medical



Determining Someone's Baseline

Mobility

- ▶ Ambulatory
- ▶ Assistance
 - ▶ Type
 - ▶ Frequency
- ▶ Wheelchair use



Determining Someone's Baseline

ADLs

- ▶ Dressing
- ▶ Meal Preparation
- ▶ Shopping
- ▶ Money Management
- ▶ Housekeeping
- ▶ Sleeping



Determining Someone's Baseline

Nutrition

- ▶ Weight
 - ▶ Current
 - ▶ Trend
 - ▶ IBW
- ▶ Type and texture of diet
- ▶ Assistance needed?
 - ▶ Type of assistance
- ▶ For tube feedings
 - ▶ Rate and time
 - ▶ Type of formula
 - ▶ Reason they are on that type
 - ▶ Volume issues?
 - ▶ Recent change and reason?



Determining Someone's Baseline

Toileting

- ▶ Continent
- ▶ Prompting
- ▶ Assistance
- ▶ Routine pattern
- ▶ Constipation issues
- ▶ LAST BM



Determining Someone's Baseline

Social

- ▶ Usual responses to various stimuli
 - ▶ Likes
 - ▶ Dislikes
 - ▶ Happy
 - ▶ Sad
 - ▶ Angry
 - ▶ Aggression
 - ▶ Pain
- ▶ Interaction with others
- ▶ Recreation



Determining Someone's Baseline

Social

- ▶ Verbalization
 - ▶ Orientation
 - ▶ Awareness
 - ▶ Reliability
- ▶ How they normally communicate (communication device)



Determining Someone's Baseline Behavioral

- ▶ Aggression
 - ▶ Toward others
 - ▶ SIB
- ▶ PICA
- ▶ Inappropriate, non-aggressive behavior
- ▶ Sexual aggression
- ▶ Yelling/screaming



Determining Someone's Baseline Medical

- ▶ Fear of medical community?
- ▶ Medical Problems
 - ▶ Big List
 - ▶ Current issues
- ▶ Taking medication
 - ▶ Route
 - ▶ Mixed with food or drink
 - ▶ Pills/Liquids/Other
 - ▶ Take on their own or needs assistance



Determining Someone's Baseline

- ▶ Mobility
- ▶ ADLs
- ▶ Nutrition
- ▶ Toileting
- ▶ Social
- ▶ Behavioral
- ▶ Medical





Most Common Chief Complaints

- ▶ "He's just not acting right"
- ▶ "She's quit eating"

A small logo is visible in the bottom left corner of the slide.

Communicating the Baseline & Changes

Examples

- ▶ 45 y/o male who usually walks with a mild limp, feeds and dresses himself, Loves to watch baseball, does not like loud noises which cause him to cover his ears, scream and run away
- ▶ He is now getting up very slowly, he doesn't want to watch baseball. We have to put the spoon to his mouth and hold his cup to his lips and he is still not taking it very well. Now when he hears loud noises he will just sit there and moan. He puts his head in his hands most of the time now, as well.

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Communicating the Baseline & Changes

Examples

- ▶ 24 y/o female who uses a wheelchair, can transfer to a chair with assistance of one person, eats a puree diet because of poor dentition, not verbal but grimaces at things she dislikes and smiles at things she likes. She hits her leg whenever she becomes angry or is in pain from anything
- ▶ For the past 2 weeks, she no longer can transfer and fell twice while trying, she seems to have a hard time swallowing and coughs sometimes when she eats, she is not smiling when she sees me (who is her favorite staff of all time), she hits her leg all throughout the day.



Diabetes

- ▶ Bring written glucose record.
- ▶ Know if the person is urinating more frequently
- ▶ Know dietary information
- ▶ Know exercise information
- ▶ Note if there have been any symptoms of hypoglycemia
 - ▶ Shaking
 - ▶ Confusion
 - ▶ Sweatiness
 - ▶ Seizures
- ▶ Medication compliance



Hypertension – High Blood Pressure

- ▶ Diet information
- ▶ Salt intake
- ▶ Exercise
- ▶ Bring record of blood pressure readings with date and time
- ▶ Medication compliance



Seizures

- ▶ Bring accurate seizure record
 - ▶ How often seizures occur
 - ▶ Length of seizures
 - ▶ What the seizure looks like
 - ▶ How long they last
- ▶ Know if there is anything that brings them on
- ▶ How is the person after the seizure (post-ictal period)
- ▶ Is there a change in pattern of the seizure or the period after
- ▶ Medication compliance



SEIZURE RECORD														
Name: _____										Case# _____				
Date	Time	How Long?	Post-Seizure?			Jerking?	After Seizure (how long?)	Reason?			After Seizure (how long?)	Signature/Title		
			Y	N	C			Y	N	C			Y	N

Abbreviations: Y=yes, N=no, L=left, R=right, B=both, HA=Headache
 877-726-4778 | ESE@eecs.com



GI - Bowel Habits

- ▶ How often
- ▶ When were the last 2-3 BMs
- ▶ Consistency
- ▶ Any episodes of constipation or diarrhea
- ▶ Vomiting episodes
- ▶ Water consumption
- ▶ Swallowing issues
- ▶ Choking spells
- ▶ PEG feedings



Respiratory issues

- ▶ Fever
- ▶ Cough
- ▶ Night Sweats
- ▶ Weight loss
- ▶ Wheezing
- ▶ Shortness of breath
- ▶ Coughing up phlegm
- ▶ Runny nose
- ▶ Sore throat
- ▶ Vomiting episodes
- ▶ Swallowing/Choking issues



Injuries

- ▶ When did it occur
- ▶ Witnessed or not
- ▶ Have name and contact info of person who saw it
- ▶ Symptoms (limp, not using hand, swollen finger etc.)
- ▶ What is the person's baseline level of functioning of the injured part



Urinary Issues

- ▶ How often does the person urinate
 - ▶ Any change in frequency
- ▶ Usual color of urine
- ▶ Any complaints of pain with urination in genitalia, stomach or back
- ▶ Straining
- ▶ Poor stream
- ▶ Sexual activity



Behavioral issues

- ▶ COULD THERE BE ANY POSSIBLE UNDERLYING MEDICAL CAUSE?
- ▶ When does it occur
- ▶ Things that start or stop the behavior
- ▶ How long has it been going on



QUESTIONS

- ▶ What are the top preventable causes of death in people with IDD?
- ▶ How can you distinguish between medical and mental conditions in people with IDD?
- ▶ How can you facilitate the best healthcare visit for people with IDD?



DID YOU LEARN ANYTHING HELPFUL TODAY?



