

Welcome to



**Mental Health Wellness
for Individuals with
Intellectual and
Developmental Disabilities**

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Medical Module



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**Mental Health Wellness for Individuals with
Intellectual and Developmental Disabilities (MHW-IDD)**

-  Certificates of completion are available for each module. Please print or save your certificate immediately following completion of the course as they will NOT be available to you at a later time.
-  It is estimated that it will take you 50 minutes to complete this module. It **does** need to be completed in one sitting as your work will be lost if you close out this program during the middle of the module.
-  You can pause or back up at any time during the training but you cannot fast forward through slides. Slides will automatically advance once the voiceover is complete.
-  Your computer should have audio to complete the training as the voiceover presents much more information than what is displayed on the slides. Do not attempt to complete this training without audio. For those who are deaf or hard of hearing, a narrative of each slide is available in the Resources section of this online training.

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**Overview of other Medical Diagnoses
Associated with IDD**

Objectives:

1. Introduce the relationship between behaviors and the communication of pain or illness
2. Provide awareness about medical and neurological conditions that may impact the mental health, mood and behavior of people with an IDD
3. Review the role of the DSW in this process

Outline:

- I. How behaviors may be an attempt to communicate physical pain or illness
- II. Medical Problems of People with an IDD: Common Challenges
- III. Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior
- IV. The Role of DSW's
- V. Summary

Outcome:
By the end of the module, learners will be able to identify frequently occurring medical and neurological conditions that may impact people with an IDD and be able to provide specific support strategies that address the diagnoses and medical problems described.

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**How Behaviors May be an Attempt to
Communicate Physical Pain or Illness**

- Have you noticed that when you are feeling well physically and when you are happy, you are much less likely to be unpleasant to someone else... even if they are unpleasant to you?  
- The **first question** we should have when someone with an IDD is becoming more agitated, having more challenging behaviors, or seems moody, **is whether or not they are feeling okay physically** 
- Think about how we can be more sensitive to what others may be feeling, but are unable to express in words

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How Behaviors May be an Attempt to Communicate Physical Pain or Illness: Role of a Direct Service Worker

- DSWs play a **critical role** in identifying signs that a person may be developing a health problem
- DSWs may recognize that a behavior change may not be behavioral or mental health related, but may in fact be due to a medical concern, causing the individual to be irritable or just feel poorly
- Keeping **good data** can also help a DSW identify problems in an individual's health condition over time
- Calling the PCP or medical professional first, rather than looking for new or more psychoactive medication solutions can make a major positive difference
- It is all about the "**why**" – why is the person having challenges now? Is there any chance he or she doesn't feel well?

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Application Exercise

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How Behaviors May be an Attempt to Communicate Physical Pain or Illness: Identifying the Need

- Recent research has shown that individuals with an IDD may be sent for psychiatric care when actually, a medical problem is causing at least some of their psychological or behavioral challenges
- Also, people may not believe their complaints because they have a reputation for "seeking attention." Often, these individuals actually do have a real health issue but it is hard to identify it
- Seeking "attention" is a normal human behavior. We all seek attention at times, unless we are withdrawn or depressed
- We need to try and figure out **WHY** the person wants attention from us, even if it is not being sought in the most effective manner because the person likely has real needs
- At times, **the need may be related to a health problem**



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How Behaviors May be an Attempt to Communicate Physical Pain or Illness: The Story of Jane

Case Example

- Jane was a 24 year-old woman with mild intellectual disability and a recent history of aggression toward caregivers and refusing help
- Prior to these behavioral incidents, she was doing well
- She **had become increasingly moody and impulsive** over the last year and even stopped going to work
- Recently, Jane was also described as having many unfounded complaints of feeling sick to "**get attention**"
- She had a checkup with her PCP but there were no clear explanations found for complaints of pain. Her PCP diagnosed her with a Borderline Personality Disorder and started her on medications



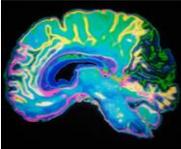
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How Behaviors May be an Attempt to Communicate Physical Pain or Illness: The Story of Jane, Continued

Case Example

- Jane was often distressed and would ask to go to the hospital, and escalated behaviorally until she was sent to the hospital
- During Jane's 3rd hospital admission, her DSW, Roger, asked that she be seen by the neurologist to have a brain scan. A brain scan called an MRI was done and it revealed that Jane had early signs of Multiple Sclerosis
- She had a long stretch of improved functioning, and this was in part because Roger recognized the changes in her behavior and mental health and helped to convey this information to the hospital staff so the **true medical problem was identified**



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How Behaviors May be an Attempt to Communicate Physical Pain or Illness: Communication

- DSWs can also work on helping and teaching people how to "tell" others that they do not feel well
- **Teaching communication skills is always helpful!**



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Application Exercise

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Medical Problems in People with IDD: Common Challenges: Overview

- People with an IDD **have more health problems than other people** without an IDD
- People with an IDD **often do not get access to effective healthcare**, and their **medical problems may get missed**, even when they are taken to see a doctor regularly
- Missed diagnosis can be caused by lack of awareness of health care providers and limited time spent with the individual
- Medical problems may also get missed because people with an IDD are often poor reporters of their own internal states (things going on inside their bodies)
- If they do not tell us what is wrong, their behavior may show us that something is wrong

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Medical Problems in People with IDD: Common Challenges: Mood Disturbances

- Some medical problems simply cause people to feel tired, irritable or moody and this can provoke challenging behaviors, or lower the threshold for these to occur
- The most important thing to remember is that whenever we support a person with an IDD, when there are changes in mood and behavior, our first job is to be sure they see a medical doctor
- **Sometimes the first or even the only signs of a developing medical problem are changes in a person's mood or behavior**
- Just like a fever tells us there is an infection but not what kind, aggression and other agitated or disruptive behaviors usually do not tell us **what** is wrong, just that **something** is wrong or that this person needs more skills to express themselves
- **Helping people be healthy and well can help them feel and function better physical and mentally**

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Medical Problems in People with IDD: Common Challenges: The Story of Mary

Case Example

- Mary had been having a lot of **urinary incontinence** and **more agitation** and challenging behaviors
- Mary had no complaints of pain when urinating or any other complaints, so her PCP did not feel that the problem was medical
- Her DSW, Rene, reported that Mary was **crying in the bathroom** recently, and **going to the bathroom over and over again**; this was also a new behavior.
- Rene also explained Mary sometimes has difficulty expressing how she feels
- Mary's PCP then decided to order a test to check for a urinary tract infection (UTI). Mary had a very severe UTI and once this was treated, she began to function much better, **having improved mood and fewer challenging behaviors**



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Medical Problems in People with IDD: Common Challenges: Diagnosing

- Remember that a person with a severe IDD is less likely to be able to clearly express their own medical distress sources, and **more likely to exhibit distress in the form of a challenging behavior**
- We may recognize that a person with severe or moderate intellectual disability who has obvious expressive language deficits will not tell us reliably about medical problems

1 in 20 ADULTS
in the United States is likely to be misdiagnosed when seeing a doctor.



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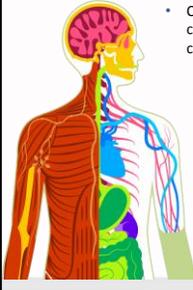
Medical Problems in People with IDD: Common Challenges: The Story of Shelly

Case Example

- Shelly, a 38 year-old woman with mild intellectual disability had a **history of very severe aggression toward caregivers**. She had been taking high doses of antipsychotic medications for her "mood disorder"
- She began to show symptoms of flu. She was helped to take Tylenol and rest, but kept getting sicker. Her DSW, Tywana, took her to an urgent care clinic, where the doctors did an exam and concluded it was just the flu and sent her home
- Shelly looked even worse the next morning, so Tywana took her to the ER where again, the doctor stated this looks like a viral infection and sent her home
- **Shelly's fever got higher and she began to have difficulty walking**. Tywana brought her back again to the ER and would not leave until a full work up was done
- It turned out Shelly had a rare, sometimes fatal adverse drug reaction called Neuroleptic Malignant Syndrome or NMS. **Tywana's persistence saved Shelly's life**

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Medical Problems in People with IDD: Common Challenges: Examples



- Common problems that may be easily missed but may cause distress and increase emotional and behavioral challenges reported in research include such issues as:

Allergies
Sinus
Infection

GERD

Osteo-
arthritis

Dental
Problems

Headache
or
Migraine

Constipation

Ear
Infection

Skin
Infection

Urinary
Tract
Infection

Sleep
Problem

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Medical Problems in People with IDD: Common Challenges: Comorbidity as a Warning

- When challenging behaviors get worse or emerge **AND** at the same time; the person with an IDD is also having sleep problems, altered patterns of eating, drinking, walking or moving, or changes in bowel or bladder habits – we may be more suspicious that a medical issue is impacting behavior



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Medical Problems in People with IDD: Common Challenges: Teaching to Communicate

- DSWs can help by **teaching people to communicate** when they do not feel well
- This starts by asking people if there might be something wrong and if anything hurts and encouraging them to let you know and doing **“check ins”**
- Rewarding people for reporting symptoms of health issues can also help**
- The person does not have to communicate verbally for you to “check in” with them
- Find the way the individual communicates and help **support them to express themselves** in a way that others will understand

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Application Exercise

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Medical Problems in People with IDD: Common Challenges: Psychotropic Medication Side Effects

Psychotropic Medication Side Effects

- Medical problems may include the **“unwanted”** effects of medications or medication side effects
- People with an IDD who have psychiatric disorders or serious challenging behaviors are often treated with one or more psychoactive medications
- Recent studies have shown that people with an IDD receive a lot of psychoactive medication compared to other populations, and there is **growing concern that there is an over-reliance on medications to control behavior**
- The more medications a person takes, the greater the risk for side effects and complications
- People with IDD can often be poor reporters of side effects



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Medical Problems in People with IDD: Common Challenges: Side Effects

- Common side effects that can cause or worsen mood and behavior include:
 - Sedation or fatigue
 - Sleep disruption
 - Irritability
 - Anxiety
 - Dizziness from changes in blood pressure when a person goes from sitting or lying down to standing
 - Muscle stiffness
 - Motor restlessness and nervousness, feeling “jumpy”
 - Headaches
 - Nausea
 - Confusion
 - Constipation
 - Dry mouth
 - Increased risks of dehydration
 - Balance problems



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**Medical Problems in People with IDD:
Common Challenges: Distinguishing the "Real" Problem**



- Sometimes, a person with an IDD will complain of not feeling well, but the complaint is not even about the real medical issue!
- This can make it seem like these complaints are "fake" and aimed at getting a reaction from others, when really, they are just a misguided way of **seeking help and relief from true distress or discomfort**
- Sometimes even doctors miss the real medical problem, and everyone "blames" the patient for complaining and having challenging behaviors

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**Medical Problems in People with IDD:
Common Challenges: Story of Jane**

Case Example

- Jane was a 21 year old female with Autism Spectrum Disorder and mild intellectual disability
- She started receiving psychiatric care related to hearing voices for the first time about 6 months prior to starting care at a specialized program for people with an IDD and mental health challenges
- Her DSWs who worked with her at home described how Jane became withdrawn after the move. She was taken to see a psychiatrist who started an antipsychotic medication
- It was realized that Jane had severe slowing and muscle stiffness from the antipsychotic medication
- When these side effects were treated and the antipsychotic stopped, Jane started to feel like her old self
- DSWs can help simply by being caring in their approach, always conveying that you really care that someone might not feel well

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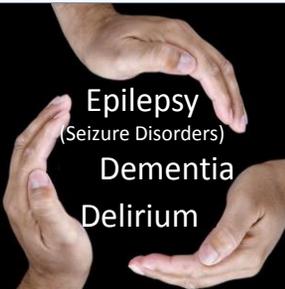
**Medical Problems in People with IDD:
Common Challenges: Role of DSWs**

DSWs play a key role in helping people with IDD by:

1. Recognizing that sometimes, individuals may look like they are having a psychiatric problem when they are actually feeling ill
2. Being sure people with an IDD who are showing signs of distress, either by a mood or behavior change, are referred for a thorough medical assessment to be sure the problem isn't related to a medical condition
3. Taking data on specific signs or symptoms that help inform assessments and treatments including things like:
 - Observing and reporting when there are any signs of a medication side effect
 - Providing positive care and support that helps people be happy, well physically and well mentally
 - Helping people eat healthy foods, get exercise and have ways to relax

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**Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior**



Common medical conditions that influence people with an IDD with a direct impact on mood and behavior

Epilepsy
(Seizure Disorders)
Dementia
Delirium

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**Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior: Seizure Disorder**

Seizure Disorder (also known as Epilepsy)

- Occur more often in people with an IDD
- **Higher rate of mental illness** than the general population
- Most common psychiatric disorders associated are anxiety, depression or bipolar disorder
- May also have mood changes because medication needed to control seizures can have side effects that cause people to feel tired, moody or run down
- Getting a "toxic" effect (the amount of the drug in your system is too high) can happen without even having a change in dose
- Sudden changes in mood and behavior or new symptoms of being off balance, confused or too sleepy should prompt a call to the doctor to check for possible toxic effects of an Adverse Drug Event (ADE), or another illness.

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**Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior: The Story of Rich**

Case Example

- Rich, a 21 year-old man with moderate intellectual disability had seizures from when he was very young
- He almost died on 2 occasions from having many seizures one on top of the other, called "**status epilepticus**"
- Rich sometimes had an "aura" reporting "feeling funny" or jittery just before he had a major seizure
- Rich began to fear having a seizure and would sometimes resist coming out of his room when he felt one might be coming on
- He started to look as if he was "off balance" and unsteady
- Raul recognized that this was not a sign of an emerging psychosis or mental illness, but that Rich was pretending to be Super Man to feel safe



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MHW=IDD Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: The Story of Rich, Continued

Case Example

- Raul also made sure the neurologist knew about the unsteadiness. Rich's neurologist checked anti-epilepsy drug blood levels, and found that one of them was very high
- Rich's support team all worked on plans to help Rich feel safe and supported, and taught him to ask for help
- His medications were adjusted, and he was no longer unsteady, and stopped trying to go back to bed every day
- Rich was diagnosed with generalized anxiety disorder in addition to his epilepsy. His psychiatrist worked closely with his neurologist, and both used information from his DSWs to modify his medications
- **Raul was crucial in reporting the necessary data to help find the solution needed to help Rich**

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MHW=IDD Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Dementia and Delirium

Dementia and Delirium

- People with an IDD can develop dementia or delirium just as anyone else can
- These conditions are missed until serious, or are diagnosed incorrectly because they share some things in common
- **Accurate identification** is so important so that people get the right treatments
- It is often more challenging to make the right diagnosis when people have intellectual and communication challenges

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MHW=IDD Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior Dementia (Slide 1 of 3)

Dementia

- A condition in which the brain is affected by a disease that harms the ways the brain operates and how cells in the brain "communicate"
- Brain cells die off and the condition will become "progressive"
- The affected person often loses the ability to retain short-term memories, although initially holds onto older memories
- **Core feature of dementia is the inability to learn new things**
- Onset is often slow and there may be an overall decline in the person's functioning, with some "ups and downs"

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MHW=IDD Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior Dementia (Slide 2 of 3)

Dementia

- People with more advanced dementias often seem confused, forget who even familiar people are, and eventually forget how to do even small daily care tasks
- This can also be associated with more anxiety and even anger, as the loss of memory and skills is both frustrating and frightening
- In early stages, the person may have some awareness of their illness and the losses they are experiencing
- A dementia will worsen and a person cannot be "cured" of these conditions, though some medications can help slow the process
- People with dementia may show changes in behavior as part of the early stages of this illness. The dementia may not yet be recognized, and the challenging behaviors observed are not recognized as being caused by the dementia

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MHW=IDD Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior Dementia (Slide 3 of 3)

Who am I?

Dementia

- Dementia usually emerges when people are much older. Most people are familiar with one type of dementia called Alzheimer's disease
- Dementia can occur in younger people under certain conditions such as in Huntington's Chorea, a progressive brain disorder that is inherited, but rare, and causes loss of cognitive or intellectual abilities, motor function and eventually leads to death
- People with Down syndrome are at higher risk of developing Alzheimer's disease and they may show signs at an earlier than usual age

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MHW=IDD Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior Dementia Support Strategies

Dementia

- **Positive behavior supports** and **cognitive adaptation therapy**, that is, helping people retain as much orientation to their surroundings and to remember as much as possible, are two evidence-informed practices that have been used to help people with dementia and an IDD
- If antipsychotic medications were prescribed, it may be possible to carefully taper these and not have to use them by replacing this intervention with positive supports
- When a correct diagnosis of dementia has been made, DSWs can still make a large difference in the quality of life of an affected person. Being gentle, patient and supportive goes a long way. Also, using visual cues, very frequent reminders and following a predictable daily routine helps people
- DSWs play a key role in helping set the conditions that help people and reduce reliance of drugs to control agitated behaviors sometimes seen with dementia

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 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior:
Delirium

Delirium

- People affected by a delirium also seem confused and forgetful, but are also often having problems staying alert, and may display oddly repetitive behaviors
- Although they are very confused one minute, they may seem fine shortly later and their symptoms come and go
- A very important difference between dementia and delirium is that **most delirium is reversible**
- Delirium usually develops faster over days or weeks rather than years
- So being sure that the causes of the changes in a person's function are correctly diagnosed is critical



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 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior:
Delirium Support Strategies

Delirium

- May be brought on by infections
- Medications or problems in our body chemistry can cause a delirium-like condition
- Delirium usually has a cause that needs to be treated urgently
- When a person with an IDD shows signs of reduced alertness, coupled with mental confusion that comes and goes, DSWs may be able to seek medical help
- A key issue is recognizing that people may behave oddly or differently, and this is not always a "psychiatric" or "behavioral" condition

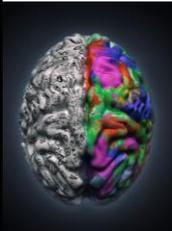
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 Application Exercise

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 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior:
Fetal Alcohol Syndrome

Fetal Alcohol Syndrome



- Very often, people who have an IDD because of exposure to drugs or alcohol during pregnancy have a specific set of challenges
- Problems with planning and problems solving, not understanding the consequences of their actions, poor ability to focus, and being impulsive
- At risk for developing challenging behaviors and problems with controlling impulses, as well as mood and anxiety disorders related to these challenges
- It is possible that people exhibit some of these challenges without a full diagnosis of FAS

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 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
Fetal Alcohol Syndrome Support Strategies

Fetal Alcohol Syndrome

- DSWs can help by recognizing how often it seems like the person "knows what they are doing" when really, he or she may not be able to handle frustration and stress because of the way their brains have been affected by exposure to alcohol and drugs before they were born
- People with this syndrome **may engage in challenging behaviors very impulsively, and feel badly after**
- It is important not to take personally something a person has said or done that might seem offensive
- DSWs can provide **more reminders about what is expected in various situations in a positive way**

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 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
Fetal Alcohol Syndrome Support Strategies, Continued

Fetal Alcohol Syndrome

- Look out for signs that the person really did not understand what they were told, or when the person may get confused about instructions
- Write things down or use frequent reminders and encouragement
- Use calendars and written schedules to help people remember what will be happening and to reduce anxiety
- **Emphasize successes and positive accomplishments**, to help with the tendency to become depressed

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 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
Acquired Brian Injury (Slide 1 of 3)

Acquired Brain Injury

- Some people have a diagnosis of IDD due to an injury to their brain that occurred before age 22
- Some are caused by an injury prior to birth leading to strokes or fluid build-up in the brain
- Can also be caused by car accidents, falls, being assaulted, or self-injurious behaviors

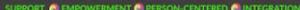




 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
Acquired Brian Injury (Slide 2 of 3)

Acquired Brain Injury

- Severity of the injury to the brain certainly plays a role, but surprisingly, this alone does not predict outcomes
- Some people with severe brain injury recover more than others whose injury initially did not seem as serious
- Even two people with a similar injury can have very different symptoms and challenges after the event
- **Many factors play a role** such as, age when the injury occurred, where in the brain the injury occurred, and the care received after the injury

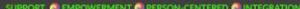


 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
Acquired Brian Injury (Slide 3 of 3)

Acquired Brain Injury

- Brain injuries can also be associated with the same kinds of learning challenges as other people with an IDD encounter:
 - Short-term memory
 - Auditory processing (understanding spoken instructions and statements)
 - Focused attention
 - Shifting attention from one thing to another
 - Regulating moods
 - Thinking about impact of actions
 - Controlling impulses (thinking before acting on an urge)
 - Understanding how others see things
 - Sequencing
- Brain injuries can cause risk for many challenging behaviors and difficulties regulating mood

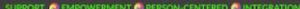




 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
Acquired Brian Injury: Support Strategies

Acquired Brain Injury

- DSWs can help people with an acquired brain injury by understanding the impact of that injury on the person's **thinking, mood and behavior**
- DSWs can provide help and support to the person specifically in view of the individual's unique profile of challenges and strengths
- People vary in how much their brain is able to repair itself after an injury
- We may need to provide people with extra help, especially "structure" including **verbal/visual cues** or **reminders/rehearsals** to promote success
- It is important to understand that each person's reaction to a brain injury is very different from person to person

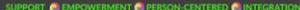


 Common Medical Conditions Influencing People with IDD:
A Direct Impact on Mood and Behavior
The Story of Joe

Case Example

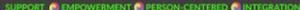
- Joe was a normally developing 17 year-old who was riding on a 4-wheel recreational vehicle while not wearing a helmet. He had a serious accident wherein he sustained a severe head injury
- Joe gradually was able to move about with physical therapy and his fractured arm healed well. Joe developed problems with his short-term memory and also became more explosive in his responses to stressful events
- Joe was very embarrassed about his deficits, and knew he was not the same as before
- His DSW who was providing help after school at home, noticed this, and helped Joe get re-involved with sporting activities. He seemed happier, and was finally smiling again and having fun after being sad or irritable most of the time





 Medical Diagnoses Associated with IDD:
Summary 

- Everything we do to promote wellness, health, happiness, social connections and positive life experiences helps reduce the risk of mental and behavioral challenges in the individuals we support
- We can learn ways to accomplish these important goals in our work by understanding the nature of medical and neurological disorders
- Remember to:
 - Be aware of known health risks and access medical care when a problem may be developing
 - Have a positive relationship with the individual to promote wellness and help to recognize changes in behaviors
 - Recognize that a medical problem may be causing irritability and an increase in challenging behaviors or emotional distress
 - Reduce demands if someone doesn't feel well





Medical Diagnoses Associated with IDD:
Summary, Continued



- Remember that things may look behavioral or psychiatric on the surface but **may be a sign of physical distress!**
- Assess for possible medical problems as a first step when a person with an IDD has sudden or major changes in their mood and behavior
- Use data tracking to monitor for signs and symptoms, and help treating clinicians detect emerging problems and design the best treatments. Track and be aware of things like patterns of eating, drinking and bowel and bladder habits
- Support teaching skills so that individuals with an IDD are better able to express themselves and tell others about physical symptoms
- DSWs are able to make a strong and powerful impact on quality of life for the people for whom they provide care
- **You can make a difference!**

SUPPORT ● EMPOWERMENT ● PERSON-CENTERED ● INTEGRATION