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Overview of Medical Diagnoses Associated with IDD and Impact on Challenging Behaviors

Slides 1, 2, and 3

No voiceover

Slide 4: 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 must have speakers or you can attach a headphone or ear bud, so that you can hear the information said by the presenter. For those who are deaf or hard of hearing, a narrative of each slide is available in the Resources section of this online training.

Slide 5: Overview of other Medical Diagnoses Associated with IDD

Welcome to “Overview of Medical Diagnoses Associated with IDD and Impact on Challenging Behaviors.”

This module is directed towards Direct Service Workers, or DSWs, as they are fundamental to supporting recovery and mental wellness in individuals with an IDD and medical problems. However, the intended audience truly extends beyond those who are paid direct service workers. While the focus is on DSWs, the information in this module applies to all caregivers and other people who support individuals with an IDD.

In this module, we will:

- 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, and
- 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

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- III. Common medical conditions that influence people with an IDD with 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.

Slide 6: 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? Or that when you feel healthy you can cope with a little stress. This is as true for the people we support as it is for ourselves! Often, 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 OK physically.

What if the only way you were diagnosed with a medical condition, or received medical help was when someone you did not know well decided you needed care or that you were not feeling well, but you could not tell the doctor yourself! How do we know someone has a stomachache? A headache? Feels dizzy? Feels too tired to do usual routines? Has cramps? A toothache? Can we see these things? Think about how we can be more sensitive to what others may be feeling, but are unable to express in words.

Slide 7: 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 see changes in behavior and recognize the person might be having a new medical problem or medication side effect, and can be supportive, and alert nursing staff or the individual's Primary Care Physician (PCP). 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. The individual might be engaging in challenging behaviors or seem unlike their usual self because of these problems, even when they are not describing a medical complaint. Keeping good data can also help a DSW identify problems in an individual's health condition over time, especially when behavioral challenges or mental health changes might have a slower progression and may not seem as sudden or unusual; when there are multiple DSWs supporting an individual; or when there are multiple factors affecting the individual's behavior. 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

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the “why” – why is the person having challenges now? Is there any chance he or she doesn’t feel well?

Slide 8: Application Exercise 1

Slide 9: 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.

Slide 10: The Story of Jane

Jane was a 24 year-old woman with mild intellectual disability and a recent history of aggression toward caregivers as well as periods of shouting at her staff, and refusing help. Prior to these behavioral incidents she was doing very well. She had gotten out of school, and moved into an apartment with DSWs, who supported her daily. She had a nice job locally where she worked at a diner and had a job coach. But 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.” Jane was always saying that her legs had pains and her back ached. She would also call her mother on the phone over and over again, which was a new behavior for her. 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 to treat her moodiness, impulsive behaviors, and aggression. Her mother, however, argued that it made no sense to her that Jane had done so well for so long and then developed such severe emotional and behavioral challenges.

Slide 11: The Story of Jane, Continued

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 third inpatient hospital admission, her DSW, Roger, asked if the inpatient team to please have Jane seen by the neurologist on site and to have a brain scan. A brain scan called an MRI was done and it revealed that Jane had early signs of Multiple Sclerosis, a disease that causes changes to the brain and often causes physical pain related to loss of muscle control. When it became clear that Jane’s complaints were real, others began to treat her with more patience; she was referred for regular checkups, and was treated

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for the MS and for pain. She had a long stretch of improved functioning, and this was at least in part because Roger had 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.

Slide 12: 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. This may mean using verbal skills or other means, such as using a communication board, or a specific type of touch or sound. It depends on an individual’s ability to communicate- take their cues and learn from them as a basis for teaching. Teaching communication skills is always helpful!

Slide 13: Application Exercise 2

Slide 14: Medical Problems of People with IDD: Common Challenges: Overview

In general, 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 a number of factors such as 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, or things going on inside their bodies, and health issues in general. If they do not tell us what is wrong, their behavior may show us that something is wrong.

Slide 15: 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. Sometimes, people engage in challenging behaviors as a way of expressing their distress. So the most important thing to remember is that, whenever we support a person with IDD, when there are changes in mood and behavior, our first job is to be sure they see a medical doctor and that possible medical causes of their distress are ruled out. Our job is always to try and assess why someone is having a problem now.

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 and meet usual needs. Helping people be healthy and well can help them feel and function better physically and mentally.

Slide 16: Medical Problems in People with IDD: Common Challenges: The Story of Mary

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Many times, medical providers and others do not have experience assessing people with an IDD. DSWs can help doctors make more accurate diagnoses. Here is an example:

Mary had been having a lot of urinary incontinence and at the same time, more agitation and challenging behaviors like yelling at her peers and staff. Mary had no complaints of pain when urinating or any other complaints, so her PCP did not feel that the problem was medical, since he knew Mary had behavior challenges for many years. However, her DSW, Rene, reported that Mary was crying in the bathroom recently, and going to the bathroom over and over again, and stated that this was also a new behavior. Rene also explained that Mary sometimes has difficulty expressing and describing how she feels, or if something is bothering her. Mary's PCP then decided to order a test to check for a Urinary Tract Infection or UTI. Mary in fact had a very severe UTI and once this was treated, she began to feel and function much better, having improved mood and fewer challenging behaviors.

Research has shown that many people with an IDD sent for psychiatric help because of mood changes and challenging behaviors were found to have medical ~~problems~~ issues that caused these problems, or at least aggravated them. In Mary's case, detecting and treating the medical problems brought resolution to the concerning mood and behavior changes!

Slide 17: Medical Problems in People with IDD: Common Challenges: Diagnosing

Remember that a person with a severe IDD is more unlikely 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, but this can even be true for people with very mild intellectual disability or even no intellectual disability, people with Autism Spectrum Disorder for example.

It is also possible to go see the doctor for a question of a health problem and have the doctor say there is no problem, when there is still a problem. Things get missed at times, and we have to be persistent if symptoms continue. Here is an example.

Slide 18: Medical Problems in People with IDD: Common Challenges: The Story of Shelly

Shelly, a 38 year-old woman with mild intellectual disability had a history of very severe aggression toward caregivers. She had been treated with many medications, and was taking high doses of antipsychotic medications for her "mood disorder." She began to show symptoms of flu. She had a fever, aches and pains and especially complained about feeling stiffness in her legs and arms. She was helped to take Tylenol and rest, but kept getting sicker and wasn't eating at all or even drinking fluids well. Her DSW, Tywana, took her to urgent care, where the doctors did a quick examination and concluded it was just the flu and sent her home. But Shelly looked even worse the next morning, so Tywana took her to the ER where again, the doctor stated this looks like a

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viral infection and sent her home. Then 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. Shelly required treatment in the ICU but she did recover fully. Tywana's persistence saved Shelly's life. The doctor's missed the NMS because the condition is very rare and looks like flu, but Tywana didn't give up when Shelly didn't get better after seeing the doctor.

Slide 19: 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 constipation, gastro-esophageal reflux disease, or GERD, dental problems, headaches or migraines, sleep problems, osteoarthritis, ear infections, skin infections, allergies and sinus infections, and urinary tract infections.

Slide 20: Medical Problems in People with IDD: Common Challenges: Comorbidity as a Warning

In general, 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. DSWs can help greatly by recognizing these patterns.

Slide 21: Medical Problems in People with IDD: Common Challenges: Teaching to Communicate

Also, 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, doing "check ins" when someone seems just not OK. Rewarding people for reporting symptoms of health issues can also help. And remember, the person does not have to communicate verbally for you to "check in" with them. There are a lot of ways we connect with each other. You have to find the way the individual communicates and help support them to express themselves in a way others will understand and be able to understand them.

Slide 22: Application Exercise 3

Slide 23: Medical Problems in People with IDD: Common Challenges: Psychotropic Medication Side Effects

We'll now move on to discussing medications and their associated side effects. Medical problems include the "unwanted" effects of medications or medication side effects. People with an IDD who have psychiatric disorders or serious challenging behaviors like aggression or self-injurious behavior are often treated with one or more psychoactive medications.

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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 over-reliance on medications to control behavior. The more medications a person takes, the greater the risk for side effects and complications. People with an IDD can often be poor reporters of side effects.

Slide 24: Medical Problems in People with IDD: Common Challenges: Side Effects

Common side effects that can cause or worsen mood and behavior, and may be missed, include sedation or fatigue. That is, medications make the individual tired or they may lose interest in activities. Other side effects include 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 and balance problems.

Slide 25: 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 vague or 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. Let’s hear an example of this.

Slide 26: Medical Problems in People with IDD: Common Challenges: The Story of Jane

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. This was a few months after she moved into a new school program. Her DSWs who worked with her at home described in detail how Jane became very anxious and withdrawn after the move. She was taken to see a psychiatrist who started an antipsychotic medication. Jane completely stopped talking, moved very slowly and stopped engaging in any of her previously preferred activities. After collecting a lot of detailed history from her DSWs and upon examination, it was realized that Jane had severe slowing and muscle stiffness from the antipsychotic medication. When these side effects were treated and then the antipsychotic stopped, Jane started to look and feel like her old self. It was clear from the reports of the DSWs who knew Jane well that Jane had really suffered from anxiety related to stressful life events (a big change in her daily routines). Her team then worked on slowly introducing her to new people and her new schedule, being aware that she needed time and support to reduce her anxiety about the changes. Her DSWs visited her at her new school to help her feel comfortable and teach her new classroom staff. They also introduced fun activities that Jane always enjoyed in the new classroom, to help her feel comfortable and enjoy being in the new school program.

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As you can see, DSWs can help simply by being caring and kind in their approach, always conveying that you really care that someone might not feel well.

Slide 27: Medical Problems in People with IDD: Common Challenges: Role of DSWs

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

Recognizing that sometimes, individuals may look like they are having a psychiatric problem, for instance, being moody, experiencing poor sleep, or refusing activities, when they are actually feeling ill.

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 that can be helped.

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 effects
- Providing positive care and support that helps people be happy, well physically and well mentally. This in turn reduces the likelihood of challenging behaviors that sometimes lead to over use of medications.
- And lastly, helping people eat healthy foods, get exercise and have ways to relax like doing yoga, walking, writing, and enjoying art and music.

Slide 28: III: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior

We will now move on to discussing common medical conditions that influence people with an IDD with a direct impact on mood and behavior. Some examples include epilepsy or seizure disorders, dementia and delirium.

Slide 29: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Seizure Disorder

Seizure disorders occur more often in people with an IDD than in people without an IDD. There are many different types of seizures, and different disorders or medical and neurological problems that may cause a person to have seizures.

People with epilepsy have a higher rate of mental illness than the general population. The most common psychiatric disorders associated with epilepsy are anxiety, depression or bipolar disorder. There are multiple possibilities as to why seizures and psychiatric symptoms are associated.

People with epilepsy 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. Sometimes, it can be difficult to control the levels of drugs in our blood. Getting a "toxic" effect (the amount of the drug in your system is too high) can happen without even having a change in dose.

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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. Let's hear the example of Rich.

Slide 30: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: The Story of Rich

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, something 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 he would sometimes resist coming out of his room when he felt one might be coming on. This happened more and more until he kept going back to bed each morning. He also started to look as if he was "off balance" and unsteady at times. Additionally, he began to tell people that he was Super Man. His DSW, 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.

Slide 31: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: The Story of Raul

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. Raul would check each hour and ask him if he needed any help, and began getting him out having fun with some of his favorite activities. 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 so he was on medications that helped his seizures and his anxiety, and helped him be more responsive to the non-medical interventions implemented by his DSWs. He gradually became less reclusive and less anxious, and began to show signs of being happy. In this example, Raul was crucial in collecting and reporting the necessary data to help find the solution needed to help Rich.

Slide 32: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Dementia and Delirium

We will now move on to dementia and delirium. People with an IDD can develop dementia or delirium just as anyone else can. Many times, these conditions are missed until serious, or are diagnosed incorrectly because they share some things in common. Like many conditions, accurate identification is so important so that people get the right treatments. However, it is often more challenging to make the right diagnosis when people have intellectual and communication challenges.

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Slide 33: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Dementia (Slide 1 of 3)

Dementia is a condition in which the brain is affected by a disease that harms the ways in which the brain operates, and how cells in the brain “communicate.” Generally, with dementia, brain cells die off and the condition will become “progressive” or, will steadily worsen over time. With dementia, the affected person often loses the ability to retain short-term memories, although initially holds onto older memories. The core feature of dementia is the inability to learn new things. The onset is often slow and there may be an overall decline in the person’s functioning, with some “ups and downs” along the way.

Slide 34: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Dementia (Slide 2 of 3)

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. Sadly, in most cases, a dementia will worsen and a person cannot be “cured” of these conditions, though some medications can help slow the process or promote a better quality of life. People with dementia may show changes in behavior as part of the early stages of this illness. At times, the dementia had not yet been recognized, and the challenging behaviors observed are not recognized as being caused by the dementia.

Slide 35: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Dementia (Slide 3 of 3)

Dementia usually emerges when people are much older. Most people are familiar with one type of dementia called Alzheimer’s disease. However, 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 that 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 than other people, and they may show signs at an earlier than usual age as well.

Slide 36: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Dementia Support Strategies

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-based practices that have been used to help people with dementia and an IDD. Also, 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. This is often a goal

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because these medications can cause a lot of serious problems in older individuals who have dementia. 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 retain skills longer and decreases frustration. 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.

Slide 37: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Delirium

Delirium can look like dementia. People affected by a delirium also seem confused and forgetful, but are also often having problems staying alert, and may display oddly repetitive behaviors like picking non-existent lint off the floor. 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, as is the case with a dementia. So being sure that the causes of the changes in a person's function are correctly diagnosed is critical.

Slide 38: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Delirium Support Strategies

Delirium may be brought on by infections. In some cases, medications or problems in our body chemistry can cause a delirium-like condition, such as having too much medication in our body or being dehydrated. 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 and report observations. A key issue is recognizing that people may behave oddly or differently, and this is not always a "psychiatric" or "behavioral" condition.

Slide 39: Application Exercise 3

Slide 40: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Fetal Alcohol Syndrome

We are now going to move on to discussing Fetal Alcohol Syndrome, or FAS. Understanding the effects of Fetal Alcohol Syndrome on thinking and learning can improve care. Very often, people who have an IDD because of exposure to drugs or alcohol during pregnancy have a specific set of challenges. These may include problems with planning and problems solving, not understanding the consequences of their actions, poor ability to focus, and being impulsive. People with Fetal Alcohol Syndrome are at risk for developing challenging behaviors and problems with controlling impulses, as well as mood and anxiety disorders related to these challenges. It is also important to note that it is possible that people exhibit some of these

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challenges without a full diagnosis of FAS. That is, someone may have been exposed to alcohol or drugs during pregnancy but they did not develop the full syndrome.

Slide 41: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Fetal Alcohol Syndrome Support Strategies

DSWs can help people with Fetal Alcohol Syndrome especially 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 this. It is important not to take personally something a person has said or done that might seem offensive, and instead stay positive toward the person. DSWs can provide more reminders about what is expected in various situations in a positive way. For example, you could say, “I know we will have a great time tonight when we go out to dinner with everyone and just remember, I am there to help you if you need it.”

Slide 42: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Fetal Alcohol Syndrome Support Strategies, Continued

DSWs can also look out for signs that the person really did not understand what they were told, or when the person may get confused about instructions. Then, the individual can be helped in a positive way by having things written down or by using frequent reminders and encouragement, as suggested. DSWs may use calendars and written schedules to help people remember what will be happening and to reduce anxiety. Lastly, DSWs can help by emphasizing successes and positive accomplishments, to help with the tendency for people with Fetal Alcohol Syndrome to become depressed.

Slide 43: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Acquired Brain Injury (Slide 1 of 3)

Let us now talk about an acquired brain injury, or ABI. Some people have a diagnosis of IDD due to an injury to their brain that occurred before age 18. Some brain injuries are caused by an injury prior to birth leading to strokes or fluid build-up in the brain. Others may be caused by car accidents; falls or even due to things like being assaulted or self-injurious behaviors, especially severe repeated head banging.

Slide 44: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Acquired Brain Injury (Slide 2 of 3)

Severity of the injury to the brain certainly plays a role, but surprisingly, this alone does not predict outcomes. Some youth 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 and where in the brain the injury occurred, but also the care received after the injury.

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Slide 45: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Acquired Brain Injury (Slide 3 of 3)

Brain injuries can also be associated with the same kinds of learning challenges as other people with an IDD encounter, including challenges in the areas of 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 and sequencing (understanding how things go in order, following a series of steps.)

Brain injuries can cause risk for many challenging behaviors and difficulties regulating mood because of the issues listed above.

Slide 46: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: Acquired Brain Injury Support Strategies

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. People can learn to walk and speak again after a stroke, and may learn other skills again. However, we may need to provide people with extra help, especially "structure" including verbal and visual cues or reminders and rehearsals to promote success. Always consider what areas of strength exist and maximize use of these, while providing positive supports.

It is important to understand that each person's reaction to a brain injury both in terms of how their brains are injured, and then how much they recover and what symptoms they have is very different from person to person. Let's hear the story of Joe.

Slide 47: Common Medical Conditions Influencing People with IDD: A Direct Impact on Mood and Behavior: The Story of Joe

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. He was in a coma for one week. Joe gradually was able to move about with physical therapy and his fractured arm healed well. However, 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. He had always loved sports. His DSW who was providing help after school at home, noticed this, and helped Joe get re-involved with sporting activities. They also reviewed sports news together and went to local ball games. Joe's mother reported how much more progress Joe was making in his rehabilitation since his DSW helped Joe become more involved again in the things he had always enjoyed. And most

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critical, he seemed happier, and was finally smiling again and having fun after being sad or irritable most of the time.

Slide 48: Medical Diagnoses Associated with IDD Summary

In 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 for whom we support. We can learn ways to accomplish these important goals in our work by understanding the nature of medical and neurological disorders associated with IDD. Better understanding of these challenges helps us provide more informed and targeted care.

Many examples were discussed that include how we can impact a person's life dramatically by being aware of changes in their behavior, mood, and daily routine, being responsive to their needs, and providing positive support. 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.

Slide 49: Medical Diagnoses Associated with IDD Summary, Continued

Remember that things may LOOK behavioral or psychiatric on the surface but could 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. Just because someone has irritable mood or more challenging behaviors, it may not be because of their mental illness alone; it may be due to a health problem.
- 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. Just being open, always asking people who are upset what's going on, and offering support goes a long way!

In the case of all of these medical and neurological problems, 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!