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




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

Click the "Next" button to begin the
Genetics Module







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


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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 Genetic Syndromes Associated with IDD

Objectives:




1. Provide overview of genetic syndromes
2. Provide awareness about shared behavioral traits and specific syndromes associated with Intellectual and Developmental Disabilities (IDD)
3. Present resources to learners on best practice treatments and supports


Outline:

- I. What is a Genetic Syndrome?
- II. How Genes Affect Behavior: Nature-Nurture Transactions
- III. What is a Behavioral Phenotype?
- IV. Common Genetic Syndromes Associated with IDD
- V. Summary

Outcome:
Learners will be able to identify common genetic syndromes associated with IDD, and be able to identify specific strategies to support people more effectively.


Acknowledgment: Much thanks to Lauren Charlot, PhD for her time and expertise in developing this module




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Introduction to Genetics

- Resources are available to aid in your learning and understanding
- **Genetics includes how human traits are passed on from generation to generation**
- We inherit many traits and tendencies from our parents, including things like eye, hair, and skin color
- As well as potential risk factors like the risk of developing high blood pressure, or even, to some extent personality traits



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What is a Genetic Syndrome?

- Each of us is a product of the genetic material that we get from our parents
- Half of the genes come from the mother and half come from the father, creating a unique genetic code, or biological blueprint, that determines our hair color, body size and even some of our behaviors
- Sometimes, people inherit genes for illnesses that the parents don't show
- Sometimes, the genes of parents combine in ways that produce a condition in their child that neither parent may have
- Sometimes the genes make errors such as:
 - Making too many copies
 - Breaking off pieces of genes
 - Recombining pieces that usually do not occur together
- These can create changes in the genetic code that are called genetic syndromes

Importance of Identifying Genetic Syndromes

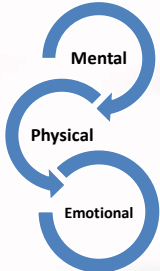
- Genetic syndromes occur when there is an abnormality in our genetic codes
- A genetic syndrome is a set of characteristics shared by people who have the same genetic blueprint
- Correctly identifying the syndrome is very important because we can then provide educated care specific to that syndrome
- Knowing syndrome-specific risks for medical and mental health disorders allows us to provide better healthcare
- Some genetic syndromes can increase risk for specific health and mental health disorders and may also be associated with certain behavior patterns
- We especially want to know if a person has a specific syndrome that poses a high risk for certain medical problems, so we can prevent problems or catch them early to promote optimal health
- When people are healthy, they are less likely to engage in challenging behaviors

How Genes Affect Behavior: Nature-Nurture Transactions

- Because of our genetics, we may be able to do, or not do, certain things better than others
- But genes do not dictate a person's whole life story
- Our genes interact with the environment around us to affect the total person and shape who we become
- The DSW has a very important role in **creating an enriched environment** for people with an IDD by adapting environmental conditions that support the individual's strengths and allow for successful teaching opportunities
- **Remember, focus on people's strengths!**

What is a Behavioral Phenotype? Introduction

- Behavioral phenotypes are the shared personality features, patterns of behavior and temperamental tendencies that are associated with having a specific genetic syndrome
- Temperament is the combination of mental, physical, and emotional traits of a person, or their natural predisposition, to respond to his or her environment
- The biological core of temperament remains relatively stable across someone's life, but the behaviors or actions can be modified by the environment



Application Exercise

What is a Behavioral Phenotype? Potential Difficulties

- It helps to know that a person may be more prone to have certain strengths or areas of greater challenge in terms of how they learn, plan and problem solve
- Individuals with an IDD have challenges in learning, whether they have an identified genetic syndrome or not


Remembering	Focusing Attention	Organizing	Time Management
Impulse Control	Self-Monitoring	Problem Solving	Planning
Social Awareness	Social Skills	Communication	

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What is a Behavioral Phenotype? Temperamental Differences

“easy going”
“easily excited”
“active, but not overly so”
“on the go all the time”

These “temperamental” differences may have a genetic component rather than being just a “learned” behavioral or emotional pattern



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What is a Behavioral Phenotype? How to Respond

- How we respond to someone, and their unique “style” of engaging the world, can make a big difference
- Once we understand the common shared behavioral characteristics of a person’s genetic syndrome and how the syndrome can impact the person’s temperament, **we can adjust the way we communicate, teach and support that individual**
- It is important to **build skills using the person’s strengths** to maximize their success and quality of life, as well as their health and personal growth
- It is important to understand the behavioral phenotype of a person with a genetic syndrome so we can better predict and even prevent common behaviors associated with that syndrome

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Common Genetic Syndromes Associated with IDD: Overview

- Increase quality of life and outcomes
- Decrease challenging behavior

For each syndrome, we will discuss:

1. Physical characteristics associated with the syndrome
2. Common medical problems that can affect behavior, learning, and health outcomes
3. Common shared traits, or behavioral phenotypes, and related support strategies

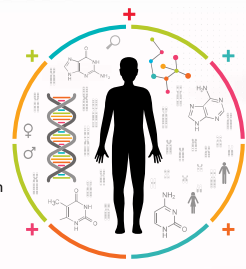
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Common Genetic Syndromes Associated with IDD: Examples

- ➕ Down Syndrome
- ➕ Fragile X Syndrome
- ➕ William’s Syndrome
- ➕ Prader Willi Syndrome
- ➕ Cornelia De Lange Syndrome

Course Resources Section - “Common Genetic Syndromes Associated with IDD”




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Common Genetic Syndromes Associated with IDD: Down Syndrome

Down Syndrome



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Common Genetic Syndromes Associated with IDD: Down Syndrome: Physical Characteristics


Down Syndrome

Physical characteristics

- Low muscle tone
- Short neck, with excess skin at the back of the neck
- Flattened facial profile and nose
- Small head, ears, and mouth
- Upward slanting eyes
- Wide, short hands with short fingers
- A single, deep, crease across the palm of the hand
- Short stature



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Common Genetic Syndromes Associated with IDD Down Syndrome: Medical Problems

Down Syndrome

Common Medical Problems

- Congenital abnormalities with vertebra in neck
- Obesity
- Congenital abnormalities of heart (usually diagnosed as infant)
- Increased risk of vision or hearing problems
- Thyroid problems including hypothyroidism (underactive thyroid gland)
- Gastroesophageal reflux, or GERD (backflow of acidic stomach contents into the esophagus)
- Constipation
- Increased risk of developing Alzheimer's disease at an earlier age (40's and 50's)

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Common Genetic Syndromes Associated with IDD Down Syndrome: Medical Support Strategies

Down Syndrome


Support Strategies for Common Medical Problems

- Screening for thyroid problems is part of "**Best Practice**" primary care
- Cervical spine abnormalities can put an individual at high risk of injury, or even death, during physical interventions such as restraint. They can also be associated with pain, cause irritability and challenging behaviors
- Obesity and congenital heart abnormalities also associated with injury and death in individuals who have been restrained
- Because of difficulties with hearing, individuals with Down Syndrome may become frustrated and confused
- **DSWs play an important role in recognizing when an individual has new or more severe challenging behavior, or irritable mood**
- It is important to let doctors know to check for medical conditions before treating challenging behaviors with only psychiatric or behavioral interventions

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Common Genetic Syndromes Associated with IDD Down Syndrome: Common Traits




Down Syndrome

Common Traits

- Mild to moderate intellectual disability; although some may have severe intellectual problems or none at all
- Mental health challenges may relate to Obsessive Compulsive Disorder or Depression
- Tend to be socially motivated and make friends easily
- Described as inflexible at times – can lead to challenging behaviors including agitated outbursts
- Rather than this being a challenge, this can actually be seen as a strength!
- Speech and language may develop later and more slowly, and speech may be more difficult to understand
- May have attention problems, and may need help focusing on tasks

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Common Genetic Syndromes Associated with IDD Down Syndrome: Support Strategies

Down Syndrome

Support Strategies


- See "oppositional" behavior as **communication of frustration**, and try to support the individual to better express needs
- Be patient, and allow time for the person to learn. Always giving choices, even if just between 2 options, helps people have control
- Acknowledge a person's feelings without agreeing to their challenging behavior
- It is important the individual knows you really want to know their opinion
- Provide **reminders and visual cues** and **use multiple ways** to get information across
- Have a **quiet place** when teaching new skills and **repeat steps**. It also helps to have the person repeat things back to ensure they understood and heard what was said

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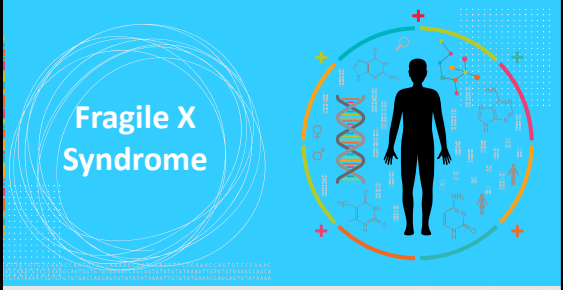


Application Exercise

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Common Genetic Syndromes Associated with IDD: Fragile X Syndrome



Fragile X Syndrome

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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Physical Characteristics



Fragile X Syndrome


Physical Characteristics

- Long and narrow face
- Large ears
- Prominent jaw and forehead
- Unusually flexible fingers



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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Medical Problems




Fragile X Syndrome

Common Medical Problems

- Ear infections
- Seizures
- High blood pressure (hypertension)
- Hernias
- Premature menopause
- Mitral valve prolapse
- Joint hypermobility where joints move beyond a normal range
- Misalignment of the eyes (Strabismus)
- Ataxia (poor coordination of muscle control)

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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Medical Support Strategies




Fragile X Syndrome

Support Strategies for Common Medical Problems

- **DSWs are often the first people to notice** that someone they support is unhappy and may not be feeling well
- People with an IDD are often poor reporters of health issues
- May have few ways to show distress, so challenging behaviors may be a sign that a person is uncomfortable or in pain
- New or worse challenging behaviors +
 - Changes in fluid or food intake
 - How much they sleep or looking tired
 - Different pattern of behavior

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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies (Slide 1 of 7)



Fragile X Syndrome


Common Traits

- Intellectual disabilities which may vary from mild to severe
- Generalized Anxiety Disorder
- Panic Disorder
- In women, depression and mood disorder is common
- Autism Spectrum Disorder or autistic features are very common, affecting about 1 in 3 (33%) individuals with Fragile X Syndrome. This impacts communication and social interaction
- A great place to learn more is at the website for Autism Speaks <https://www.autismspeaks.org>



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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies (Slide 2 of 7)




Fragile X Syndrome

Common Traits

- People with Fragile X have sensitivity to noises
- Crowds, and touch, are also a frequent trigger


Support Strategies

- Avoid excessive sensory or emotional stimulation, such as noise, and crowds
- Be considerate to the individual's sensory sensitivities
- Remember that sometimes noises that don't bother you may be too much for the person with Fragile X



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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies (Slide 3 of 7)



Fragile X Syndrome

Common Traits

- People with Fragile X may have challenging behavior because of anxiety
- High anxiety can sometimes cause risk for "fight or flight" behavior
- This can lead to aggression or self-injurious behavior
- Hand biting is common
- Rapid speech may be mistaken for a mental illness, specifically "mania"

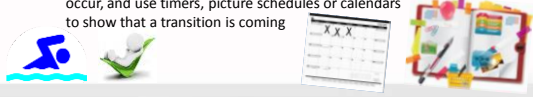


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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies
 (Slide 4 of 7)

Fragile X Syndrome
Support Strategies

- Anxiety can come from not knowing what to expect
- Tell the individual what is happening and **maintain a predictable routine**
- Use tactics that help the person be less anxious. Examples might be swimming, taking walks, or using other relaxation tools
- It is useful to **provide reassurances** often, versus “prompts”
- People with more severe functional limitations may need much more structured support, such as using a visual schedule
- Set up predictable routines so the person knows when transitions will occur, and use timers, picture schedules or calendars to show that a transition is coming



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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies
 (Slide 5 of 7)

Fragile X Syndrome
Common Traits

- Often present with anxiety, impulsive, and hyperactive behavior such as fidgeting or impulsive actions
- Attention deficit disorder (ADD) is common (impaired ability to maintain attention and difficulty focusing)

Support strategies

- Consider what supports are in place for the individual and if they are appropriate or need modification
- People with Fragile X can lead fulfilling lives, have friends, and employment
- DSWs can make a difference** in thoughtful planning and modifying the environment to meet the needs of the individual to set them up for success!




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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies
 (Slide 6 of 7)

Fragile X Syndrome
Common Traits

- Being very shy
- May be unsure of how to make friends
- May have “social anxiety” meaning meeting new people causes them anxiety, but they will enjoy being social when given help and time to build relationships
- “Gaze aversion” (poor eye contact)




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Common Genetic Syndromes Associated with IDD
Fragile X Syndrome: Common Traits and Support Strategies
 (Slide 7 of 7)

Fragile X Syndrome
Support Strategies

- Plan activities in the community that will not be overwhelming to the person and make sure that the right supports are available
- Be thoughtful in your social interactions and eye contact
- Arrange the person’s environment in ways that **maximize individual learning style**
- Try to arrange a good fit between strengths, skills and interests, and daily activities. For instance, a person who is very shy and dislikes noise will work better in a situation where it is not too loud and crowded
- Teach simple social skills like how to greet someone you are meeting for the first time and taking turns when talking to others



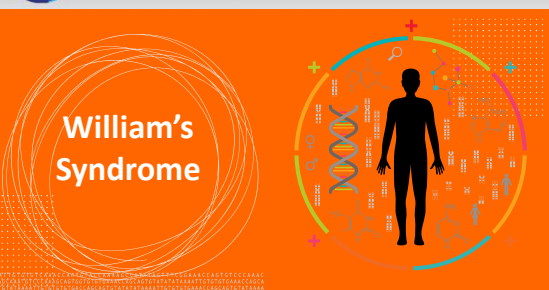
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Application Exercise

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Common Genetic Syndromes Associated with IDD:
William’s Syndrome

William’s Syndrome




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Common Genetic Syndromes Associated with IDD:
William's Syndrome: Physical Characteristics

William's Syndrome

Physical Characteristics

- An "Elfin" facial appearance with a small upturned nose
- Short stature
- Wide mouth with full lips
- Partially missing teeth, defective tooth enamel, or small, widely spaced teeth
- Sloping shoulders



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Common Genetic Syndromes Associated with IDD
William's Syndrome: Medical Problems

William's Syndrome

Common Medical Problems

- Heart valve problems
- High blood pressure
- Problems with coordination
- Gastrointestinal problems
 - Chronic constipation
 - Stomach pain
 - Rectal prolapse
- Urinary tract infection
- Urinary incontinence

Support Strategies for Common Medical Problems

- Always rule out medical issues that may be occurring


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Common Genetic Syndromes Associated with IDD
William's Syndrome: Common Traits and Support Strategies
(Slide 1 of 6)

William's Syndrome

Common Traits

- Intellectual disabilities which range from mild to moderate
- Mental Health Conditions
 - ADHD
 - Anxiety
 - Phobias
 - Depression




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Common Genetic Syndromes Associated with IDD
William's Syndrome: Common Traits and Support Strategies
(Slide 2 of 6)

William's Syndrome

Common Traits

- Tend to be extremely sociable and endearing, and tend to take an extreme interest in other people
- Speaking and social skills are big strengths
- Often described as having an overly friendly demeanor, and may trust strangers when they should not
- Have difficulty understanding social cues and this makes it harder to form lasting relationships
- Not being able to form meaningful and lasting relationships with others can lead to depression




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Common Genetic Syndromes Associated with IDD
William's Syndrome: Common Traits and Support Strategies
(Slide 3 of 6)

William's Syndrome

Support Strategies

- It is important to protect them from unsafe interactions such as leaving with a stranger or telling a stranger too much about themselves
- Opportunities for social interaction are important
- Support individuals to have meaningful social experiences in their daily lives, such as getting involved in community activities, church events, sports teams, or other types of social events
- Many adults with William's syndrome can contribute to their communities as volunteers or paid employees



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Common Genetic Syndromes Associated with IDD
William's Syndrome: Common Traits and Support Strategies
(Slide 4 of 6)


William's Syndrome

Common Traits

- Strengths on tasks that involve spoken language, music, learning by repetition, facial recognition, and short-term auditory memory
- Challenges with visual-spatial tasks (drawing and assembling puzzles), hand-eye coordination, and fine motor control
- Difficulties in numbers, perceptual planning, and abstract reasoning

Support Strategies

- Try to make learning fun, social & use a tool the person enjoys
- Be thoughtful in setting expectations and working on skill building
- Someone may take on more than s/he is able, which can increase overall anxiety
- Be careful not to make assumptions based on first impressions



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Common Genetic Syndromes Associated with IDD
William's Syndrome: Common Traits and Support Strategies
 (Slide 5 of 6)


William's Syndrome

Common Traits

- May be hypersensitive to loud sounds
- Loud sounds or physical contact can sometimes cause anxiety

Support Strategy

- It is key to avoid places with loud noise



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Common Genetic Syndromes Associated with IDD
William's Syndrome: Common Traits and Support Strategies
 (Slide 6 of 6)


William's Syndrome

Common Trait

- People with William's Syndrome also often have special musical talents!
 - KanDoo Band link: <http://www.kandoooband.com/home>

Support Strategies

- Anxiety is often at the core of any kind of challenging behaviors
- Music is a great way to promote wellness and create a calming environment for these individuals
- **Celebrate the individuals you support!**

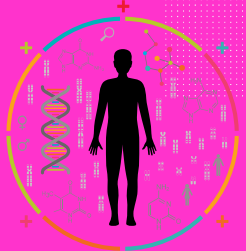


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Common Genetic Syndromes Associated with IDD:
Cornelia de Lange Syndrome

Cornelia de Lange Syndrome



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Common Genetic Syndromes Associated with IDD
Cornelia de Lange Syndrome: Physical Characteristics

Cornelia de Lange Syndrome

Common Physical Characteristics

- Small and widely spaced teeth
- Small upturned nose
- Low-set ears
- Arched eyebrows that often meet in the middle
- Long eyelashes
- Some limb abnormalities, as in their legs or arms
- Excessive body hair
- Short stature
- Microcephaly



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Common Genetic Syndromes Associated with IDD
Cornelia de Lange Syndrome: Medical Problems

Cornelia de Lange Syndrome

Common Medical Problems

- Gastro-Esophageal Reflux Disease, or GERD
- Heart problems
- Vision problems
- Hearing loss
- Sleep disturbances
- Seizures and a
- Cleft palate (an opening in the roof of the mouth)

Medical problems seen in people with this syndrome are highly variable from one affected person to the next!

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Common Genetic Syndromes Associated with IDD
Cornelia de Lange Syndrome: Medical Support Strategies

Cornelia de Lange Syndrome



Support Strategies for Common Medical Problems

- Do not promote eating close to bed time and know what foods make this condition worse
- Do not promote wearing tight clothing
- Challenging behaviors may be provoked by pain or discomfort from GERD
- Some clues that GERD may be a problem include problems sleeping and vomiting
- Need to be screened for a number of health problems. DSWs may advocate for this to happen and help support the person if he or she is anxious about medical appointments
- Using stories and visual boards to explain what will happen at the medical appointment can be helpful to reduce anxiety

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Common Genetic Syndromes Associated with IDD
Cornelia de Lange Syndrome: Common Traits


Cornelia de Lange Syndrome

Common Traits

- Intellectual disability that typically range from moderate to severe
- Depressed mood and anxiety are also common
- Obsessive-compulsive features and compulsive self-injurious behavior, specifically skin picking
- Correlated with high rates of Autism Spectrum Disorder
- Significant sensory abnormalities
- Social shyness
- Can also enjoy making friendships with others

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Common Genetic Syndromes Associated with IDD
Cornelia de Lange Syndrome: Support Strategies





Cornelia de Lange Syndrome

Support Strategies

- Because of obsessive compulsive features and anxiety, the use of visually presented, predictable, structured, daily schedules are very helpful
- Riding, swimming and other similar activities help sensory challenges
- Use visual aids, pictures or technology such as an ipad to help with communication
- To reduce anxiety, it is useful to very slowly introduce new things
- Helping people have fun and meaningful activities as well as helping insure that health problems are addressed, can help prevent depressed mood

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Common Genetic Syndromes Associated with IDD:
Prader Willi Syndrome

Prader Willi Syndrome

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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Physical Characteristics



Prader Willi Syndrome


Physical Characteristics

- Almond shaped eyes
- Thin upper lip
- Small downturned mouth
- Small hands and feet
- Nasal sounding speech
- Short stature



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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Medical Problems



Prader Willi Syndrome

Common Medical Problems



- Obesity (type 2 diabetes mellitus, high blood pressure and others)
- Sleep apnea
- Bone density problems
- Seizures, and
- Low muscle tone

Support Strategy for Common Medical Problems

- Promote exercise to increase overall wellness

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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 1 of 6)

Prader Willi Syndrome

Common Traits


- Intellectual disabilities - typically mild or borderline intellectual functioning; may have no intellectual difficulties at all
- Common mental health conditions include:
 - Anxiety
 - Obsessions and compulsions
 - Depression
 - Bipolar disorder
 - Psychotic disorders
 - Impulse control disorders
 - Hoarding, over-concern with symmetry and exactness & difficulty with changes in routines
- May engage in some serious self-injurious behaviors, especially skin picking

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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 2 of 6)

Prader Willi Syndrome
Support Strategies

- Psychoactive medications can be helpful at times, but in some cases they can make symptoms worse, especially if the medication used increases appetite
- Use other tactics such as
 - Encourage exercise
 - Assist the individual in having a meaningful day
 - Follow an individual's positive behavior support plan




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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 3 of 6)

Prader Willi Syndrome
Common Trait

- The most distinctive trait is an excessive food drive!
- Challenging behavior is often driven by obsessions with, and anxiety around, obtaining food
- The obsession with food is so strong in some people will even eat food out of the garbage and frozen foods




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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 4 of 6)

Prader Willi Syndrome
Support Strategies

- Provide carefully controlled diets and support around access to food
- Plan meals ahead of time and a regular and dependable meal schedule
- Avoid being vague about meal times
- A watch may be helpful to alleviate a person's anxiety
- Be sensitive to the fact that the person cannot help the desire for more food; their brains do not signal that they are full
- Provide predictable routines and small healthy snacks more often
- Do NOT give individuals "treats" or "rewards" as this may actually cause them more anxiety
- Remember to always follow the dietician, physician, or psychologist's orders regarding food for each individual




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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 5 of 6)

Prader Willi Syndrome
Common Traits

- Being very social
- Often have mild cognitive challenges and are aware of their challenges and differences
- They may feel shame about their challenges and can have poor self-esteem
- Tend to have strengths in the areas of:
 - Long-term memory
 - Reading
 - Visual-spatial functioning

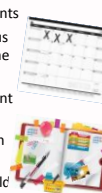


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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 6 of 6)

Prader Willi Syndrome
Support Strategies

- Help to focus on their strengths and positive accomplishments
- Positive Behavior Supports (PBS) can be very helpful to focus on individual strengths and interests, have fun and divert the focus from food, or other obsessive tendencies like hoarding
- Use of a reward system to reinforce positive and replacement behaviors, but do not use food as a reinforcer
- Use of visual daily schedules to help set up expectations can alleviate anxiety Include meal schedules on a calendar
- Never tell a person with this syndrome that you will withhold food due to behavior
- Always follow an individual's Positive Behavior Support Plan!



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Common Genetic Syndromes Associated with IDD
Prader Willi Syndrome: Common Traits and Support Strategies (Slide 6 of 6)

Application Exercise

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MHW #IDD **Individuality**

- **Every individual is unique!**
- People with the exact same micro-deletion will have differences in how they develop
- Every individual has unique skills and strengths as well as challenges, unique dreams and visions and unique potential




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MHW #IDD **Case Study Judy**

Case Example

- Judy, a 28 year old woman with Down syndrome and moderate intellectual disability, had been struggling with depression
- Judy lived in a group residence, but spent many weekends with her parents
- Judy also had hypothyroidism, and had a heart problem when she was a child
- She started to look very sad again, after the family pet passed away
- She showed some improvement with anti-depressant medication, but was not really getting back to her usual self
- When feeling well, Judy was a very warm, funny and social person who was very creative
- Her DSW found out that a local church was having a holiday event and she arranged for Judy to have a spot, and helped her get started making ornaments
- Judy really brightened up after this and began to be more active and happier




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MHW #IDD **Supporting Individuals with Genetic Syndromes**


- Understanding a person's genetic syndrome provides valuable information in helping you to establish a foundational relationship and using strategies to maximize a person's opportunities for success
- Getting to know the individual for who they are, outside of their genetic syndrome, will help you support mental wellness and help them to achieve positive outcomes
- You can make a large difference, even for people with a definite genetic syndrome, by helping them have an enriched environment and positive experiences that build on their unique individual strengths
- Medical treatments helped Judy to some degree, but these were not enough to get her back to feeling well again
- The efforts of her DSW were the most powerful influences on her feeling and functioning better

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MHW #IDD **Genetics Syndromes: Summary** 

- By understanding unique traits, strengths, and challenges associated with Genetic Syndromes, we can provide more informed and targeted care
- Recognize when someone may have a genetic syndrome associated with IDD
- Know the individual's medical conditions and recognize how feeling ill may be shown in mood and behavior, or may even look psychiatric on the surface
- Understand the importance of learning about these syndromes and how they impact a person's physical and mental health
- Follow professionals' recommendations
- Listen, communicate and be patient when they may have trouble remembering, learning or understanding.
- Provide more reminders and use tools like visual aids to help the person understand what is expected and what will happen next
- Pair verbal instructions with modeling, as well as visuals, and repeat instructions

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MHW #IDD **Genetics Syndromes: Summary, Continued** 

- Be sure people can have fun when learning and that they are taught practical skills with a focus on their strengths, interests, and learning styles
- Use Positive Behavior Supports to teach and reinforce skills, and make changes to the individual's environment to set them up for success
- Recognize the powerful influence a DSW can have on outcomes, even for people with a genetic syndrome
- Develop opportunities for people with an IDD to help them be engaged and connected socially, informed by our understanding of the person's developmental profile and behavioral phenotype
- Focus on how "normal" they are instead of how "different" they are
- In the case of all of these syndromes and disorders, DSWs are able to make a strong and powerful impact on quality of life for the people for whom you provide care
- **You can make a difference!**

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