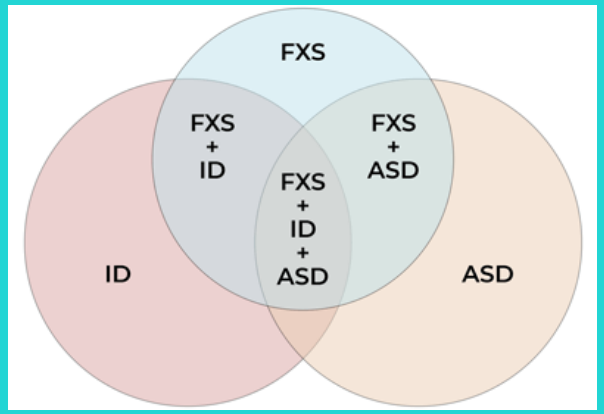
DSM-5/IDEA

- Students with FXS may meet a wide variety of DSM-5 diagnostic and IDEA disability criteria, some of which being Autism Spectrum Disorder, Intellectual Disability, OHI (ADHD), Developmental Delay, or Specific Learning Disability.

- Fragile X syndrome is the most common cause for intellectual disabilities that can be inherited. It is also the most common genetic cause for autism; 40% of children with FXS are diagnosed with autism.



Assessment

Because of the many areas of need that students with FXS may have, assessment should be comprehensive and multi-method to capture:

- Cognitive and academic achievement abilities
- Social/emotional, behavior, and adaptive functioning
- Parent and teacher reports of behaviors in multiple settings

INTERVENTIONS

There are no treatments available for Fragile X syndrome itself. Instead, the condition is managed by supporting the individual's unique needs. Some of these supports might be:

- Medication to support emotional disabilities or attention deficits.
- Teaching self-calming strategies to avoid emotional outbursts
- Providing time for extra breaks during class
- Using noise-reduction headphones, dimming lights, providing quiet areas, and limiting classroom distractions
- Occupational therapy or assistive technology

RESOURCES

National Fragile X Foundation

www.fragilex.org

FRAXA Research Foundation

www.fraxa.org

Fragile X Facebook Groups

The Fragile X Group

Fantastically Fragile X – the FX Brag Room

Fragile X Awareness

FRAGILE X SYNDROME

Learn more about the syndrome that affects 1 in 4,000 males and 1 in 8,000 females.

COMMON NAMES

- FXS
- Martin-Bell Syndrome
- Fra(X) syndrome
- FRAXA syndrome
- Marker X syndrome

WHAT CAUSES FRAGILE X?

Fragile X syndrome is an **inherited disorder** caused by a mutation in the FMR1 gene. Within the FMR1 gene, a DNA segment is expanded. This DNA segment is repeated 5-40 times in someone without the syndrome, however, people with fragile X syndrome have it repeating more than 200 times. The expansion of the segment creates a disruption in nervous system functions and can make the X chromosome look “fragile”, which is how the syndrome got its name.

Fragile X syndrome is inherited in an X-linked dominant pattern. Males only have one X chromosome, so fathers can only pass it onto their daughters. On the other hand, females have two X chromosomes and their permutation of the gene can develop into eggs, which means that women have an increased risk of having a child with fragile X syndrome. Women can pass the permutation to both their sons and daughters. Women , males often experience more severe symptoms compared to females.

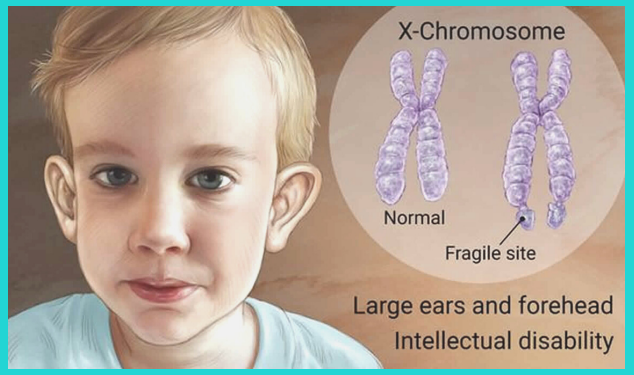
CHARACTERISTICS

Most males and some females have characteristic physical features including:

- A long and narrow face
- Large ears
- A prominent jaw and forehead
- Unusually flexible fingers
- Flat feet

Symptoms that 80-99% of individuals with fragile X syndrome have also include:

- Chronic infections of middle ear
- Joint laxity



DEFICITS

Cognitive Functioning
Emotional Regulation
Verbal Communication
Attention Deficits
Social Functioning
Daily Living Skills

LONG TERM

DEVELOPMENTAL OUTCOMES

Fragile X is a chronic illness that does not get worse over time, but can present in different ways depending on the developmental stage of the individual. Early intervention may prevent difficulties from worsening.

- Children with fragile X have a range of intellectual abilities. Some children may have average intellectual abilities. Others have problems ranging from mild learning disabilities to severe intellectual disability.
- Most children with fragile X have trouble with coordination and strength. Young children may be slow in developing motor skills.
- Many children with fragile X have difficulty learning to interact peers and developing age appropriate friendships.