

# WILLIAMS SYNDROME

## Background

Williams syndrome (WS) is a genetic developmental disorder characterized by mild to moderate intellectual disability, distinct facial features, and unique social characteristics. An array of medical problems range in severity and age of onset, but the majority affect the cardiovascular and gastrointestinal systems. Low muscle tone and connective tissue abnormalities are also common.

Children with WS have distinct facial characteristics which include small, upturned nose, wide mouth, prominent lips, small chin, and puffiness around the eyes. Teeth are often small and widely spaced. Such features tend to grow more distinct with age.

Other characteristics or complications include:

- Developmental delay
- Heart and blood vessel problems (e.g., cardiovascular disease, hypertension)
- GI issues can affect bowel motility, growth, pain, reflux
- Low muscle tone
- Dysphagia
- Joint laxity, unsteady gait
- Bone malformations
- Scoliosis
- Hypothyroidism
- Early puberty
- Hearing sensitivity
- Hernias
- Chronic ear infections, risk for hearing loss
- Constipation
- Sleep problems

Delays in the start of language development are common at a young age but striking verbal abilities are generally a strength as the child ages. A strong relationship exists between individuals with WS and music. Their affinity for music contributes to their auditory strengths.

Children with WS are excessively empathetic and outgoing. Their personalities are pleasant and sociable by nature. Children with WS tend to engage more easily with adults than peers their age. They can also experience anxiety or specific phobias contributing to outburst of aggression or difficult behavior.



## Top Takeaways for School Considerations

Most students with Williams syndrome (WS) will have some mild to moderate delay in their cognitive development.

Expressive language and social skills may be a relative strength.

A student with WS may be very social and engage more easily with adults versus peers. Developing a safety support system should be considered.

Low muscle tone and poor visuo-spatial awareness can make tasks like handwriting difficult.

Affinity for music can be useful to help engage children with WS in the classroom.

Individuals with WS may lack the understanding to sense what others may be feeling or thinking. Use of play scenarios and social stories may help foster social skills and friendships with peers.

## Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of risk for unstable blood pressure, risk for injury and impaired thought process
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Nutrition interventions and equipment needs
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

## Discussion Starters for Educational Team

1. Has the school staff been trained to implement the student-specific emergency plan?
2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
4. Does the student need additional adult support to access the academic curriculum in the least restrictive environment?
5. Can rest breaks, safe spaces or reduced stimulation times be built into the student's schedule?

## Resources

Kennedy Krieger Institute: Neurology and Neurogenetics Clinics  
[kennedykrieger.org](http://kennedykrieger.org)

Williams Syndrome Association  
[williams-syndrome.org/](http://williams-syndrome.org/)

Williams Syndrome Foundation  
[williams-syndrome.org.uk/](http://williams-syndrome.org.uk/)



Scan QR code or visit  
[KennedyKrieger.org/HealthInformation](http://KennedyKrieger.org/HealthInformation) for more information.