



## Williams Syndrome

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Williams Syndrome (WS) is an incredibly rare genetic developmental disorder that impacts approximately 1 in 10,000 births worldwide. WS is caused by the deletion of genes on the 7th chromosome and is diagnosed by a FISH test, which examines an individual's DNA. People with WS can present with many wonderful traits, such as an affinity with music and a friendly personality. However, they tend to struggle with spatial awareness and fine motor tasks. People with WS can also present with many physical characteristics, which include:



- distinct craniofacial (face) appearance, characterized by upturned nose, long upper lip, small chin, starburst pattern in the eyes, puffiness around the lower eye
- mild to severe heart problems, such as narrowing of blood vessels and high blood pressure
- low birth weight and slow weight gain into adulthood
- kidney problems
- musculoskeletal issues, characterized by low muscle tone, joint stiffness, and a limited range of motion

Williams Syndrome presents very differently from individual to individual, so having a team of professionals to diagnose and treat the symptoms of WS produces the best outcomes. These professionals include cardiologists, endocrinologists, nephrologists, audiologists, otolaryngologists (ENT), ophthalmologists, orthopedists, physical therapists, occupational therapists, and speech-language pathologists. A speech-language pathologist (SLP) has a unique role on the team based on the presentation of the person with WS. This presentation could include:

- Feeding Difficulty As children, many people with WS suffer from dysphagia, which is difficulty swallowing. This could be caused by low muscle tone in the lips, cheeks, and tongue. Infants with WS could present with the inability to coordinate sucking and swallowing while feeding. Children with WS could also suffer from sensory issues with feeding, such as a severe gag reflex or tactile defensiveness. An SLP specialized in diagnosing and treating pediatric swallowing disorders would work with the child to make feeding time safer and easier.
- Atypical Dentition (teeth) Many people with WS suffer from abnormal dentition, which could lead to problems with feeding and articulation. An SLP in conjunction with a craniofacial team could make recommendations as far as treatment of articulation disorders to help the individual be understood easier.
- Attention Deficits Children with WS struggle with staying on task for extended periods of time. They often have difficulty focusing in a busy classroom. Many children with WS exhibit hypersensitive hearing, which adds to distractibility. SLPs can help by recommending strategies to help children stay on task.
- Language Delays Although expressive language is a relative strength with those with WS, many children with WS do not have the same language ability as typically developing peers. WS presents with a range of mild to severe cognitive and language delays. As with other children with language delay, early detection and treatment is critical for later success.





- Pragmatic Deficits Although people with WS are very social, some exhibit trouble interpreting social cues and figurative language, which can cause them to become isolated. Children with WS are often more drawn to speak with adults than same age peers. Although people with WS are very polite, they are often described as "overly friendly" and may approach strangers without inhibition. An SLP can work with that individual to develop skills for appropriate social interactions and help him/her interpret difficult social situations.
- Difficulties with Daily Living Skills Due to cognitive deficits, many people with WS require assistance into adulthood. An SLP can assist with activities of daily living (ADLs), such as understanding the directions of a prescription, reading a bus schedule, and coordinating hygiene routines. Many people with WS contribute to their community by volunteering or working in part-time positions. SLPs can help navigate the routines and social interactions of these opportunities.
- Hearing Loss Some hearing loss is common as people age. However, in people with WS, this hearing loss happens earlier than typically developing peers, especially with the perception of high frequency sounds. It is important to for a person with WS to undergo regular audiological screenings around 30 years of age. As hearing loss develops, an SLP can assist with different modes of communication to supplement residual hearing.

In addition to a medical and therapeutic team, the Williams Syndrome Association is a great resource for people with WS and their families. Not only does the association provide current information regarding treatment and outcomes for people with WS, it also is a great way to meet other individuals and families impacted by WS.

Resources:

https://williams-syndrome.org/what-is-williams-syndrome

https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589943975&section=Signs and Symptoms

For more FREE Handy Handouts°, go to www.handyhandouts.com

### **Helpful Products**

The list of Super Duper® products below may be helpful when working with children who have special needs. Visit www.superduperinc.com and type in the item name or number in our search engine. If you're viewing this Handy Handout on a computer, click the links below to see the product descriptions.

#### Difficult Situations Fun Deck®



Item #FD-156

#### Pre-Handwriting Fun Deck®



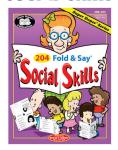
Item #FD-234

#### MagneTalk Match-Up 204 Fold & Say® Adventure Kit



Item #GB-181

# Social Skills



Item #BK-293