

KNOW BEFORE YOU KNOCK



DOWN SYNDROME



Every child and family has unique aspects of their situation, experience, and diagnosis. This page is intended to provide a general overview but is not attempting to represent every situation or child you encounter. Every family deserves your expertise to assess and adapt your prior knowledge. This resource is best viewed electronically.

DEFINITION

"Down syndrome is a genetic condition caused when an unusual cell division results in an extra full or partial copy of chromosome 21. This extra genetic material causes the developmental changes and physical features of Down syndrome." (1)



NATIONAL/STATE ORGS

["The Down Syndrome Association of Wisconsin's"](#) mission is to provide support to Wisconsin families and individuals with Down syndrome and related disabilities through awareness, education, information, programs, services, and the exchange of ideas and experiences."

[The National Down Syndrome Society's](#) mission is: "To empower individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions."

CONSIDERATIONS THAT MAY IMPACT SERVICES

Medical Complexity Including:

- Sleep apnea
- Ear infections
- Intestinal blockage, gastroesophageal reflux disease (GERD) or celiac disease (1)
- Heart problems (44%)
- Altered Immune system- Hashimoto's disease, type 1 diabetes, alopecia, celiac disease, juvenile idiopathic arthritis, and vitiligo (2)
- Leukemia
- Dental problems
- Seizures (1)

LANGUAGE TO USE/AVOID

Ok to use: "Congratulations!", Baby/child with Down Syndrome.

[What to Say to the Parents of a Baby With Down Syndrome: Dos and Don'ts](#)

Avoid: The R-Word, "downs baby," "special," "They don't even look like they have Down Syndrome!", "I'm sorry," ranking the severity of the syndrome.

TOP RESOURCES

- [The Lucky Few Foundation](#)
- [Down Syndrome Resource Foundation](#)
- [Interventions to improve sensory and motor outcomes for young children with central hypotonia](#)
- [The Emerging Down Syndrome Behavioral Phenotype in Early Childhood Implications for Practice](#)
- [YouTube Video - Eva's Story](#)

PREVALENCE

1 in 775 babies (2)

DIFFERENCES THAT MAY BE PRESENT

Delayed motor milestone (3)

- Low muscle tone
- Spinal problems-atlantoaxial instability (1) (should be screened by medical team - no upside down play if found)
- Flat Feet (12)
- Joint dislocations (1)
- Decreased early postural control, motor speed, balance (4)
- Substitution of thumb for index finger
- Difficulty learning pincer grasp (5)

Speech

- Vocal abnormalities
- Delayed and disordered speech sounds
- Fluency and prosody differences
- Intelligibility challenges (6)
- Hearing differences (1)
- Visual imitation is stronger than vocal imitation (8)

Social

- Increased smiling behavior
- Increased eye contact with caregivers, but decreased social referencing
- Inconsistency in motivational orientation" (8)

Cognitive

- Challenges with spatial memory and visuoconstructive tasks
- "Visual memory visual-motor integration and especially visual imitation seem to be areas of relative strength" (8)

Adaptive

- Feeding
 - Low suction tone and swallowing disorders (9)
 - Oral hyposensitivity and hypersensitivity
 - Delayed oral motor skills (10)
- Vision-Nystagmus (11)

REFERENCE LIST

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