DOWN SYNDROME

Background

Down syndrome is the most common chromosomal condition associated with intellectual disabilities. Chromosomes are small "packages" of genes in the body that determine how a baby's body forms and functions as it grows and develops. There are three types of Down syndrome, but the physical features and behaviors are similar. **Trisomy 21** is the most common form of Down syndrome which occurs when there is an extra copy of chromosome 21. Down syndrome can cause a wide range of physical, cognitive, and behavioral challenges.

There are over 50 clinical signs of Down syndrome, but every child with Down syndrome is a unique individual. Common physical traits of Down syndrome include smaller stature, an upward slant to the eyes, a smaller mouth and larger appearing tongue, unusually shaped or small ears, and a single deep crease across the center of the palm. Other physical features associated with Down syndrome include:

- Low muscle tone
- Excessively loose joints
- Ear, nose, and throat problems (e.g., ear infections, hearing deficits)
- Eye disease, vision loss
- Congenital heart defects
- Obstructive sleep apnea
- Thyroid dysfunction
- Gastrointestinal (GI) tract abnormalities (e.g., chronic constipation, intermittent diarrhea, gastroesophageal reflux, obstruction)
- Swallowing difficulties, uncoordinated chewing
- Seizures

Children with Down syndrome are considered a higher-risk group susceptible to infection. They are more likely to suffer respiratory infections of the upper airways (e.g., ear infections, sinusitis) and lower airways (e.g., bronchiolitis, pneumonia) related to structure of the facial features and and functions of the heart and lungs. Low muscle tone and difficulties with chewing and swallowing may increase the child's risk of aspiration.

Most children with Down syndrome experience some degree of intellectual disability. Children may be delayed in meeting developmental milestones and have specific challenges with attention, memory, expressive communication, and impulsivity. Children with Down syndrome have strong social skills, often using non-verbal communication. They may talk out loud to themselves as a way of understanding and processing information.

Top Takeaways for School Considerations

Most children with Down syndrome will experience cognitive delays ranging from mild to moderate.

Recognize that unusual behaviors or situational responses may signal an oncoming illness that the child is unable to communicate.

Children with Down syndrome express pain more slowly and less precisely. Refer student to school nurse for any signs that child is experiencing pain.

Low muscle tone and joint laxity may affect physical abilities like gait and endurance. School staff should plan for the student's increased energy requirements and safety.

Ocular and orbital anomalies are common in children with Down syndrome. Vision and hearing screenings and follow-up are important.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of delayed growth and development, self-care deficit, impaired verbal communication, risk for injury, risk for infection
- 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)
- Respiratory interventions and equipment needs
- Nutrition interventions and equipment needs (consider brand/size of feeding tube, tube replacement, water flushes, fluid intake goal and supplements); note school district policy on tube replacement and consider keeping backup feeding tube kit at school if applicable
- 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. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
5. Does the student need additional adult support to access the academic curriculum in the least restrictive environment?
6. Would schedule flexibility support the student?
7. Does the student need support with gross or fine motor skills in the classroom?

Resources

Kennedy Krieger Institute: Down Syndrome
kennedykrieger.org/patient-care/conditions/down-syndrome

Supporting the Student with Down Syndrome in Your Classroom: Down Syndrome Association of Greater St. Louis
dsagsl.org/wp-content/uploads/2014/04/Supporting-the-Student-With-DS-Information-for-Teachers.pdf

Supporting the Student with Down Syndrome in Your Classroom: Down Syndrome Association of West Michigan
dsawm.org/wp-content/uploads/2019/11/Educator-Manual-No-date.pdf

Scan QR code or visit
KennedyKrieger.org/HealthInformation for more information.

Kennedy Krieger Institute