

22q Deletion Syndrome in the Classroom

A Teachers Reference

Basic Information

What You Need To Know

1. Most children (90%) with 22q deletion experience some degree of developmental disability with delayed speech and language development as the most consistent feature.
2. In formal standardized testing, most school aged children have a full scale IQ in the category of borderline intellectual disability (full scale IQ of 71-85).
3. A school aged child with 22q deletion will typically have an unusual neuropsychological profile with a significantly higher verbal IQ than performance IQ with strengths and weaknesses suggestive of a nonverbal learning disorder.

Common strengths

- ✓ Simple, focused attention
- ✓ Rote verbal learning and memory
- ✓ Ability to remember well-encoded information
- ✓ Spelling and grammar
- ✓ Computer skills
- ✓ Word processing speed
- ✓ Kinesthetic abilities (such as dance or karate) However, low muscle tone is common.
- ✓ Rhythm and musical talent
- ✓ Willingness to learn

Common difficulties

- ✓ Language – both receptive and expressive language
- ✓ Visual-spatial skills & memory
- ✓ Non-verbal processing
- ✓ Abstract reasoning
- ✓ Fine and gross motor skills
- ✓ Executive and adaptive functioning
- ✓ Social & emotional functioning, including high levels of anxiety
- ✓ Complex verbal memory
- ✓ Working & encoding memory
- ✓ Reading comprehension

Attention and Memory

What You Need To Know

- ✓ Diagnosis of attention deficit disorder is common in 22q deletion.
- ✓ Attention to details but not the whole
- ✓ Problems with concentration on tasks
- ✓ Executive function difficulties affect planning, thinking flexibly and understanding abstract ideas.
- ✓ This may cause children to struggle to remember, process, and organize information efficiently.
- ✓ Executive function difficulties can cause problems in more complex math or in reading comprehension.
- ✓ May also affect social interactions because of the difficulty in planning and executing plans

Interventions for attention and memory

- ✓ Repeatedly using verbal instructions
- ✓ Break down instructions into clear steps
- ✓ Use a tape recorder while reading to the class
- ✓ Allow student to use a word bank on a test to help with recall
- ✓ Teach a system of remembering assignments using a chart and/or an assignment book

Math

What You Need To Know

Individuals with 22q deletion syndrome may have significant visuospatial dysfunction, diminished math attainment, and executive dysfunction.

- ✓ Deficits may be seen in areas of nonverbal processing, visual-spatial skills, complex verbal memory, attention, working memory, visual-spatial memory, and mathematics.
- ✓ Math learning difficulties in 22q deletion include difficulties in understanding and representing quantities and in accessing the numerical meaning from symbolic digits.
- ✓ Individuals may show adequate fact retrieval while development of procedural strategies appears to be delayed.
- ✓ Word problems may be a significant area of weakness. They are challenging due to their procedural nature and difficulty in reading comprehension.

Interventions for learning math

- ✓ Provide a template for complex or multistep problems; break down the steps
- ✓ Help teach the concepts of numeracy and the associations between numbers and quantities. For example using a board game in which the playing pieces are moved around a board.
- ✓ Line up the numbers for calculations
- ✓ Use active learning to teach concepts, such as baking or cooking to teach fractions
- ✓ Help the child learn to apply the information in new circumstances

Motor and Sensory

What You Need To Know

- ✓ *Motor and sensory abilities in children with 22q deletion syndrome may be delayed.*
- ✓ Poor muscle development in children with 22q deletion syndrome may lead to delayed motor milestones.
- ✓ This can lead to coordination problems that can persist into adolescence. Children may find it difficult to perform tasks that require dexterity and control of movements.
- ✓ Children may struggle with visual information to guide their actions. They may find it difficult to perform tasks requiring spatial awareness.
- ✓ Copying down text is difficult, as it requires coordination and the ability to hold information in memory for the short term.

What You Can Do

- ✓ Occupational, speech and physical therapy may be helpful for motor development, feeding and swallowing, etc.
- ✓ Visual instruction may work better than verbal.
- ✓ Limit written homework

Behavior & Sensory Support

What You Need To Know

- ✓ Social withdrawal is common and may be in part due to speech problems.
- ✓ Attention deficit is common and may make the behaviors in a classroom challenging.
- ✓ Anxiety, perseveration and autism spectrum disorders can also be present and contribute to social withdrawal.

Interventions for Behavior & Sensory Support

- ✓ Advocate for continued speech therapy to address speech differences
- ✓ Be alert for signs of autism and advocate for appropriate support
- ✓ Monitor for the need for additional support services for anxiety or depression

Notes:

Studies show that kids with 22q experience anxiety in everyday situations, even though they might not show the typical signs of distress that teachers will recognize. This is largely based on the common language deficits shared by children with 22q. These deficits make it more challenging for a teacher to identify anxiety that might be more obvious in other children who also requires IEP's. Both parents and teachers should be vigilant in identifying underlying anxiety, and work jointly (in the home and at school) to address this common pitfall as partners in your child's education process.

Communication

What You Need To Know

Speech and language development is delayed in the majority of children with 22q deletion syndrome. This may be due in part to structural differences such as a cleft palate (a hole in the roof of the mouth) or to functional difficulties (either VPI or oral apraxia).

Hypernasal speech is common (75%).

- ✓ Excessively nasal speech due to velopharyngeal incompetence (VPI)
- ✓ VPI is a condition in which the soft palate does not close properly and the oral cavity is not closed off completely from the nasal cavity during speech.
- ✓ Some children with VPI experience nasal regurgitation in which food and drink comes out the nose.

Articulation disorders

- ✓ May be compensatory
- ✓ May be due to oral apraxia (inability to coordinate facial and lip movements) or dysarthria (weakness of oral muscles)
- ✓ Slow vocabulary growth and difficulty in forming complex sentences is also common.

Be alert for warning signs of problems:

- ✓ Late or missing assignments and/or unfinished work
- ✓ Work attempted, but done incorrectly
- ✓ Quietness in class – lack of questions
- ✓ Difficulty retelling a story
- ✓ Social or behavioral problems

Interventions for Communication

It is important to rule in/out developmental motor speech disorder. This includes:

- ✓ Childhood apraxia of speech which is a motor planning problem
- ✓ The diagnosis and the treatment of speech and language problems are challenging. *Many different factors may be involved. However, remediation has led to excellent prognosis in a large majority of cases.*
- ✓ As a result of nasal regurgitation, the child may experience more nasal infections.
- ✓ This gap between the velum and pharynx (area in the back of the throat) may also lead to difficulty swallowing, or dysphagia.
- ✓ It is important to remember that feeding may be a challenge for these children, and they may tire easily during mealtimes.
- ✓ For more information on speech-language disorders, see:
<http://www.asha.org/public/speech/disorders/>.

Physical Activity, Trips, Events

What You Need To Know

- ✓ Hypotonia (low muscle tone) is sometimes still an issue in the school years and may impact the child's ability to participate in a physical education program.
- ✓ Special accommodations needed for individuals who have 22q deletion syndrome are dependent on the individual child.
- ✓ A child with 22q deletion with ADHD or executive function challenges, may wander or be confused on a field trip.
- ✓ Speech difficulties may make field trips and special events more challenging.

What You Can Do

- ✓ Involving the parent in the planning is important so that the special needs for special event or field trips can be addressed.
- ✓ Assist in developing an adaptive physical education program if needed.

School Absences and Fatigue

What You Need To Know

- ✓ Additional surgeries may cause increased absences.
- ✓ In rare cases the immune deficiency can cause an increased susceptibility to infections.
- ✓ Anxiety or depression may cause increased absences and school phobias.

What You Can Do

- ✓ Work with the student and parents to communicate about absences for medical reasons and help provide the extra help needed.
- ✓ Be alert for signs of anxiety or depression and contact the parents.

Emergency Planning

What You Need To Know

Emergency plans will be very individually determined and many children with 22q deletion syndrome will not have a need for a specific emergency plan.

Resources

GEMMS

<http://www.gemssforschools.org/conditions/22q-deletion-velocardiofacial/default.aspx>

The International 22q11.2 Deletion Syndrome Foundation

<http://www.22q.org/>

Velo-Cardio-Facial Syndrome Education Foundation, Inc.

<http://www.vcfsef.org/>

National Center for Biotechnology Information (NCBI) Bookshelf - 22q11.2 Deletion Syndrome

<http://www.ncbi.nlm.nih.gov/books/NBK1523/?report=printable>

Educating Children with Velo-cardio-facial Syndrome

http://www.pluralpublishing.com/publication_phfec.htm

Cutler-Landsman, Donna. San Diego: Plural Publishing, 2007. Print.

ISBN10: 1-59756-109-6

ISBN13: 978-1-59756-109-9

Educational Issues for Children with Chromosome 22q11.2 deletion

http://www.ucdmc.ucdavis.edu/mindinstitute/research/cabil/presentations/dultz_education-nov05.pdf

Strategies for School Success with 22q/VCFS/DiGeorge

<http://www.elwyngenetics.org/DCL.pdf>

Missing Genetic Pieces “Strategies for Living with VCFS by Sherry Gomez

http://books.google.com/books?id=BbrgJwtlX0sC&pg=PA145&lpg=PA145&dq=22q+%2B+IEP+accommodations&source=bl&ots=mqzXp_iNvV&sig=G5QuCzpG9cU8dJHohja-q3nCblo&hl=en&sa=X&ei=1nJkULbtNcn8rAGI6YDYBq&sqj=2&ved=0CEwQ6AEwCQ#v=onepage&q=22q%20%2B%20IEP%20accommodations&f=false

Velo-Cardio facial Syndrome/22q11.2 Deletion Syndrome -An Introduction for Teachers & Caregivers

<http://www.vcfdfa.org.au/media/PDF7%20Teachers%20&%20Carers%20Guide.pdf>

Wrights Law <http://www.wrightslaw.com/>