

## Reading Comprehension

### What You Need to Know

Most children with 22q deletion will perform close to the average range in terms of reading ability, however reading comprehension is a relative area of difficulty for children with the syndrome.

### What You Can Do

- Acquisition of sight vocabulary should be encouraged, in conjunction with a traditional phonics-based approach
- Use direct instruction to help the child look for 'clues' in the question and finding the answer in the passage
- Provide guidance about how a character is feeling or what they may be thinking, make predictions together about the text

## 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.
- Communication difficulties may make field trips and special events more challenging.

### What You Can Do

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

## Motor and Sensory

### What You Need to Know

- Motor and sensory abilities in children with 22q deletion syndrome may be delayed. 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 language, and physical therapy may be helpful for motor development, feeding, and swallowing, etc. ensure the child has been followed up for same
- Visual instruction may work better than verbal.
- Limit written homework where appropriate



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## Math

### What You Need to Know

- 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 challenge due to their procedural nature and difficulty in reading comprehension.

### What You Can Do

- Using direct instruction to teach useful strategies will yield most success rather than a discovery approach to teaching mathematics
- 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

## Mental Health

### What You Need to Know:

Studies show that children 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 communication difficulties shared by children with 22q. These difficulties may make it more challenging for a teacher to identify anxiety. Both parents and teachers should be vigilant in identifying underlying anxiety, and work jointly (in the home and at school) to address the child's needs. Be alert that bullying may be an issue and monitor accordingly.

### What you can do:

- Monitor for the need for additional support services for anxiety or depression e.g. CAMHS or clinical psychology and recommend referral where necessary
- Provide options to reduce sensory overload (quiet space, ability to leave room and go decompress)
- Keep staff consistent as much as possible
- Provide language support where possible in the classroom to help child follow procedures and understand expectations
- Provide multiple opportunities to explore and learn by doing
- Keep predictable routine with embedded structure
- Use visual schedule and cues to assist with transitions

## 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 child 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.

## Further Resources

22q11 Association of Ireland  
[www.22q11ireland.org](http://www.22q11ireland.org)

Alex Kelly 'Talkabout' social skills program  
<http://alexkelly.biz>

Elklan Speech and Language Resources  
<https://www.elklan.co.uk>

Genetic Education Materials for School Success (GEMMS)  
[www.gemmsforschools.org/conditions/22q-deletion-velocardiofacial/default.aspx](http://www.gemmsforschools.org/conditions/22q-deletion-velocardiofacial/default.aspx)

The International 22q11.2 Deletion Syndrome Foundation  
<http://www.22q.org/>

National Centre for Biotechnology Information (NCBI) Bookshelf - 22q11.2 Deletion Syndrome  
[www.ncbi.nlm.nih.gov/books/NBK1523/?report=printable](http://www.ncbi.nlm.nih.gov/books/NBK1523/?report=printable)

Educating Children with Velo-cardio-facial Syndrome/22q11DS  
[www.pluralpublishing.com/publication\\_phfec.htm](http://www.pluralpublishing.com/publication_phfec.htm)  
Cutler-Landsman, Donna. San Diego: Plural Publishing, Print.  
ISBN10: 1-59756-109-6 ISBN13: 978-1-59756-109-9

Educational Issues for Children with Chromosome 22q11.2 deletion  
[www.ucdmc.ucdavis.edu/mindinstitute/research/cabil/presentations/dultz\\_education-nov05.pdf](http://www.ucdmc.ucdavis.edu/mindinstitute/research/cabil/presentations/dultz_education-nov05.pdf)

Parent resource for children with learning and attention needs  
[www.understood.org](http://www.understood.org)

Strategies for School Success with 22q/VCF/DiGeorge  
[www.elwyngenetics.org/DCL.pdf](http://www.elwyngenetics.org/DCL.pdf)

Social Skills autopsy  
[www.ricklavoie.com](http://www.ricklavoie.com)  
there are also several instructional YouTube videos  
e.g. : <https://www.youtube.com/watch?v=fxuEjRxtAA>

Social stories information  
<https://carolgraysocialstories.com/social-stories/>

Velo-Cardio facial Syndrome/22q11.2 Deletion Syndrome -  
An Introduction for Teachers & Caregivers:  
<http://www.vcfsfa.org.au/media/PDF7%20Teachers%20&%20Carers%20Guide.p>

Donna Cutler-Landsman and Anne Lawlor speaking about 22q and how to raise awareness about this rare disease on The Heart of Teaching podcast. Hibernia College <https://bit.ly/2Ufy6U>

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## 22q11.2 Deletion Syndrome in the Classroom: A Teachers Reference

## Basic Information

22q11.2 deletion syndrome (shortened to '22q deletion' for this information sheet) is a genetic condition caused by a tiny missing piece on chromosome 22. This condition is highly variable in its severity and in the number of body systems that are affected. There is a difference in severity even between affected individuals in the same family. The most commonly affected areas are the heart, the palate (roof of the mouth) and speech, learning and behaviour.

It is important to meet with parent(s)/guardian(s) to learn about the child's individual medical needs. Although many of the early medical needs may have resolved by the time the child starts school, each individual child is different and may have ongoing issues that are being addressed and may impact that child's success in the classroom.

## What You Need to Know

Every child with 22q deletion is unique and possesses their own unique strengths and challenges

Most children (90%) with 22q deletion experience some degree of developmental disability with delayed speech and language development as the most consistent feature.

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).

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 challenges suggestive of a nonverbal learning difficulty.

A school aged child should undergo a full educational psychology assessment in order to understand his/her individual needs. The child should have an educational psychology review every two years after this as the cognitive phenotype shows change over time.

There is a higher prevalence of hearing impairments (38%) in children with 22q deletion.

There is a higher prevalence of visual impairments (e.g. refractory errors) in children with 22q deletion.

There is a higher prevalence of eating/drinking/ swallowing impairments in children with 22q deletion.

Multidisciplinary collaboration is essential to optimise outcomes for children with 22q11 deletion e.g. audiology essential to assess hearing functioning; psychology essential to assess and monitor neurocognitive functioning and maximise educational performance; speech and language therapist to manage eating/ drinking/ swallowing and communication needs etc.



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## Common Strengths

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

## Common Challenges

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 / Memory / Executive Functioning

### What You Need to Know

Diagnosis of attention deficit disorder (predominantly the 'inattentive' subtype) is common in 22q deletion.

Attention to details but not the whole

Difficulty with concentration on tasks

Working memory difficulties are common with 22q deletion - this is the ability to simultaneously store and process information. This impacts on the ability to successfully complete everyday tasks, as well as on general problem solving as children find it difficult to integrate information and assemble it into a meaningful structure.

Executive function difficulties are common in 22q deletion- this affects planning, thinking flexibly and understanding abstract ideas. Deficits in this area 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. Difficulties in this area also affect social interactions because of the difficulty in planning and executing plans

### What You Can Do

Ensure the child has had an educational psychology assessment

Ensure child is linked in with a clinical psychologist as needed as 'cognitive behavioural therapy' (CBT) can be an effective tool in targeting executive functioning difficulties

Use picture schedules to help the child get organised

Give plenty of notice that an activity will change using verbal and visual cues.

Repeat verbal instructions

Use visual aids to supplement verbal instructions

Break down instructions into clear steps

Use a tape recorder while reading to the class

Allow the child 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

## Social Skills and Behaviour Support

### What You Need to Know

- Social communication and social skills difficulties are common and may lead to social withdrawal
- Attention deficit is common and may make the behaviours in a classroom challenging.
- Anxiety, perseveration and autism spectrum disorders can also be present and contribute to social withdrawal.

### What You Can Do

Be alert for signs of autistic spectrum disorder and advocate for appropriate support

### Strategies for supporting social skills:

Use 'social stories' as much as possible in the classroom to help children navigate challenging social situations.

**Narrating:** some children do not know how to interpret a social situation or may not know what to do or say. Tactfully pull the child aside and interpret the situation. For example: 'Susan was being sarcastic when she said she loves doing homework for four hours'.

**Conversation skills:** Directly teach the child about basic conversation skills for example; greeting, asking questions, sharing information etc. The Alex Kelly 'Talkabout' resources are very useful for this. See 'resource list' below

**Conflict resolution:** Help the child become aware when they have hurt someone else's feelings or made a social 'misstep' by explaining the situation and the observed behaviour. For example: 'When you took over the game, and changed the rules, that was frustrating for Johnny. That's why Johnny made a face and didn't want to play anymore'. Teach the child how to 'repair' by apologizing.

**Consider the 'Social Autopsy' approach** (Lavoie 1994) A social autopsy involves discussing the following in relation to a 'social misstep':

- o What the child did
- o What happened when the child did it
- o The direction of the outcome, (i.e. was it positive, negative, or neutral)
- o What the child will do next time

See 'Further Resource page for more information

## Communication

### What You Need to Know

There is a higher prevalence of speech and language difficulties (90%) in the 22q deletion group population including: specific language impairment (40%), receptive and expressive language difficulties, speech sound delay/ disorder, motor speech difficulties (e.g. dyspraxia) and voice difficulties (pitch, volume, control). The child may also present with hyper-nasal speech (75%); this is excessively nasal speech due to velopharyngeal incompetence (VPI). VPI is a condition in which the soft palate does not close properly, resulting in the oral cavity not being closed off completely from the nasal cavity during speech. Hyper-nasal speech may also be caused by structural issues e.g. a cleft palate.

### Be alert for warning signs of speech and language difficulties:

- Difficulty communicating
- 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 behavioural problems

### What You Can Do

- Ensure the child is linked in with a local speech and language therapist
- Liaise frequently with the child's speech and language therapist (s) (please note that the child may also be linked in with a speech and language therapist as part of the cleft team in order to address VPI or palate issues, as well as their local speech and language therapist) in order to be aware of the child's communication needs.

### Strategies for working with children with receptive language needs:

- Reduce your speed of delivery and sentence length
- Briefly pause (1-2 seconds) between each piece of information
- Always use young person's name prior to asking/telling them something
- Provide oral instructions in sequential order (i.e. what comes first, next and last)
- Repeat and, if needed, rephrase after
- Use visual aids e.g. multimedia

### Strategies for working with children with expressive language needs:

- Link new curriculum vocabulary to the real life experience of the child
- Use forced alternatives with initiating responses e.g. 'Is it X or Y?'
- Use 'Category Trees' or 'Mind Maps' when teaching curriculum vocabulary (see Elklan resources for more information)
- Make semantic connections when teaching new words e.g. describe it, where might you find it, what does it do? What else is like it?
- Have a 'Word Wall' in the classroom
- Ask child questions if he/she uses 'filler words' e.g. 'what do you mean by 'stuff' or 'things?' 'Do you mean?...'
- Support the sequence of a narrative by asking
  - o What happened first?
  - o Then what happened?
  - o Where was that?
  - o When did it happen?
  - o In the end what happened?
- If child gives correct answer with incorrect syntactic or grammatical structure, model the sentence back in correct way

### Strategies for working with children with speech sound delay/ disorder:

- If you cannot understand a student and you have asked them to repeat themselves, it might help to ask the student to show you or say it in a different way. For example, ask the student to write the word if they are able to do so. Encourage the child not to give up on the message they are trying to convey to you.
- If the student's response contains a known sound error, it's important to repeat what the child said with an appropriate model. (e.g., if the child says 'nake' for snake, you would say, "Oh, you want the snake"). This way you are not focusing on the error or calling negative attention to the child, but providing an appropriate model.
- Public speaking e.g. a presentation in front of the class may be a source of anxiety for children with unclear speech. Extra support and preparation for these types of activities may be required.



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