



22q Foundation Australia & New Zealand

Introduction to 22q11.2 Deletion Syndrome
For Parents, Care Givers and Teachers

HIGH-SCHOOL

This introductory guide to 22q11.2 DS will offer basic information on some of the specific learning problems and medical issues associated with the condition. For individuals with 22q11.2DS these issues may impact on their ability to learn and therefore their education. Educating any child can be a challenge and rewarding at the same time. Educating a child with 22q11.2DS is no different. However, students with 22q11.2DS will require specialised assistance with some of their challenges. The amount and type of assistance required will vary as each case is different and each child should be treated individually.

1. What is 22q11.2 Deletion Syndrome (22q11.2DS)

22q is a genetic syndrome caused by a submicroscopic deletion of genetic material from the long arm of chromosome 22. More than 180 anomalies have been reported in people with 22q11.2DS, but expression of the syndrome is highly variable from person to person and no individual has all the anomalies. 22q11.2DS has broad reaching effects on development and behavior, speech, language, personality, mood, learning, attention, and temperament.

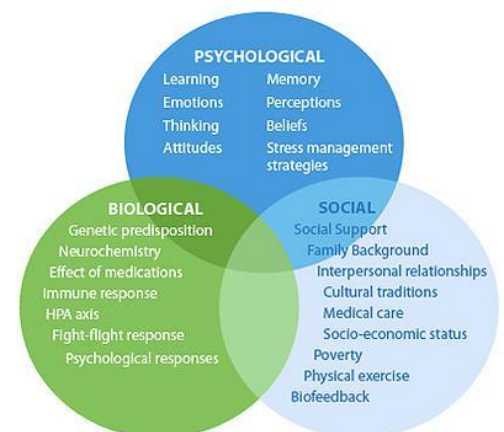
2. General Information about people with 22q11.2DS

- Many students with 22q11.2DS have had **multiple surgeries** once they reach school age.
- **Developmental delay** is present in most students with 22q11.2DS, however this doesn't tend to be recognisable until the child is around 8 years of age.
- Students should be fully assessed in all areas including: speech, language, gross and fine motor skills and have a full **psychometric report (ideally every 2 – 3 years)**.
- An **Individual Education Plan (IEP)** is instrumental in assisting the students to reach their full potential through their schooling journey
- A **communication book** is an important way of keeping everyone informed about the current goals and techniques being used to help a student with 22q11.2DS
- Students with 22q11.2DS **can achieve** with encouragement, personalised strategies and patience.

Whatever the student's difficulties, there are ways in which they can be helped to learn. The student, parents, teachers and carers are the keys to success. Constant monitoring is essential to ensure the student is receiving the best possible education. A student with 22q11.2DS **can be successful** and become an independent adult with assistance from teachers, parents and support staff.

3. Personality & Social Skills - Individuals with 22q11.2DS may:

- Have an **obsessive** personality.
- **Worry** about future events rather than what is happening right now.
- Become **anxious and stressed** without structure or routine.
- Have **speech and language problems**, making it hard to communicate with their peers
- Appear **very immature** making it difficult to keep up with their peers.
- Be **literal thinkers** and interpret words verbatim. Most students will learn the meanings of idioms without being taught, but students with 22q11.2DS may need to be taught the meaning of these very common idioms eg: "you drive me up the wall" or "I've lost my head".
- Have **trouble reading facial expressions**, following conversations and appear not to listen, changing the subject to whatever is on their mind.



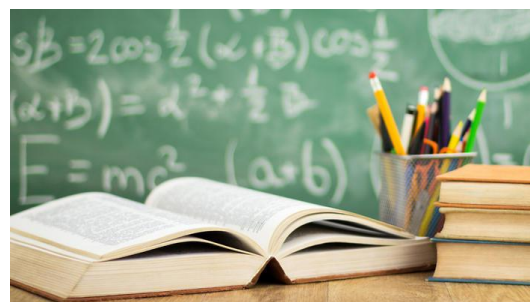
4. Motor Skills, Physical Education and Sport

- **Gross motor problems** may hinder performance in sport.
- Tasks involving **balance and co-ordination** may be extremely difficult making them appear clumsy.
- Games and **Physical Education** may be difficult if they involve words such as left, right, up, down, backwards, forwards, etc.
- **Medical problems** such as Congenital Heart Disease (CHD) may also impact on the child's ability to fully participate.
- **Chronic leg pains** are typical for children with 22q11.2DS. While this is not life threatening it can be quite unpleasant for the child so allowing them enough time to recover is important.
- **Regulating body temperature** is often an issue. Encourage them to always have a drink bottle with them. Rest them frequently on hot days and ensure they are adequately hydrated.



5. Education and Schooling – General Information

- Children with 22q11.2DS do well early on as the learning is concrete.
- Letter recognition, sounding out words for reading and times tables is usually learnt well due to the repetition/rote learning.
- Comprehension can be difficult once extracting meaning from a paragraph or page is required.
- Concepts are difficult to grasp, even things as seemingly basic as “opposite” or “reverse.”
- Learning is best done by repetition and breaking things down into the smallest units, use revision to ensure the concepts are retained by the child.
- For most children with 22q11.2DS, specific learning difficulties become obvious by 7 to 10 years of age. 22q11.2DS research shows that IQ scores change or drop frequently over time. This drop does not represent a loss of intellect; rather, it reflects the specific type of learning flaws that children with 22q11.2DS have. Focusing on the specific areas within the IQ testing is required to develop strategies for both strengths and weaknesses.



While each student with 22q11.2DS will have a unique learning profile there are areas that are common to most with 22q11.2DS. Some of the learning difficulties reported are:

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|---|--|
| <ul style="list-style-type: none">• Poor organisational skills• Difficulty discriminating size, shape, colour & difficulty with time concepts• Difficulty with abstract reasoning and/or problem solving.• Disorganised thinking.• Poor short term or long-term memory. Poor visual perception• Overly excitable during group activities | <ul style="list-style-type: none">• Poor adjustment to environmental changes. Difficulty making decisions• Poor performance compared to IQ• Difficulty concentrating.• Difficulty copying accurately from a model. Slowness in completing work• Easily confused by multiple instructions. Difficulty with tasks requiring sequencing• Hyperactivity |
|---|--|

Identifying which of the issues relate to a student with 22q11.2DS in your educational setting will help you plan their individual learning goals. Giving the student with 22q11.2DS **a chance at success** is paramount. Setting unrealistic goals will only cause anxiety and stress not only with the student but also within the family unit.

Relative to their overall intellectual functioning and nonverbal skills, many students with 22q11.2DS show a strong ability to learn and retain repetitive verbal information. Their performance often improves when they receive frequent feedback and are asked to focus on tasks that are brief and highly structured. Their verbal strengths often include memory of factual information, knowledge of words, and an understanding of practical/concrete situations.

Students with 22q11.2DS usually have more success with:

- A direct approach to learning rather than a discovery-based approach.
- Rote memorization, repetition, and concrete examples
- Instruction on how to learn, including memory techniques and test taking skills. Small group instruction or assistance within a large group/regular classroom
- Several small tasks rather than multiple directions or large assignments
- A structured environment with clear rules to follow
- Additional opportunities for participation in individual and group physical activities

- Computer assisted learning
- Reading aloud and books on tape
- Additional handouts or notes to assist with difficulties with note taking and large group presentations
- Study notes prior to a test
- Use multi-sensory activities
- Visual aids

Common areas of relative strength include:

- Simple focused attention & initial auditory attention. Verbal comprehension, word reading and decoding
- Auditory perception & memory
- Rote verbal learning & memory
- Arithmetic
- Willingness to learn

High school can bring many new challenges for a student who has 22q11.2DS. The larger school size and new school expectations, new peers, new subjects and getting used to having multiple teachers, even organising to have the correct books and equipment can be challenging for any student but more so for those with learning issues. There are several things that can be done to make the transition easier for the student.

Before they start:

Collect all **relevant documentation** from the existing educational setting. Have a meeting with the educational team from the primary school, the student and parents so that the specific learning needs of the student are known. Have a **transition plan** in place until the formal IEP is completed. Ensure reports for funding are up to date.

At their orientation days:

- Have an **example timetable** and a **map** of the school. Discuss how they will get to each lesson.
- Have the student meet as many teachers as possible.
- Run an **extra transition day/s for students with disabilities or learning difficulties** so they have an extra opportunity to familiarise themselves with the new educational setting.
- **Introduce them to the school counselor** so they know who they can talk to if they feel overwhelmed or anxious settling in.



When they start:

- **Buddy systems** are used successfully in many schools.
- **Encouraging** the student to practice writing important information down in a diary.
- **Colour coding their books** and textbooks (a different colour for each subject). This is useful for easy identification.

Homework

Teachers play a vital role in the selection, assignment, and use of homework. When homework assignments are meaningful and relevant, student achievement increases. Some things to consider:

- **Modify** the homework to the learning needs of the 22Q11.2DS child. Set it out in a clear and precise manner.
- **Specify** the amount of time to be spent each evening on homework. Take this into consideration when assigning tasks.
- **Consider alternatives** to long-term written assignments.
- **Explain** the homework and give the student extra handouts to assist them.
- When **setting** the amount of homework take into consideration that students are given homework from many different teachers and therapists.



Tests/Exams

Some students with 22q11.2DS struggle with anxiety and the pressure of exams. The results of the test may therefore not reflect the ability of the student. Strategies to help may include:

- **Give extra time** to complete the exam. Give a **verbal test** instead of written. Sit the test in a **separate room**.
- Have the **font size** of the exam paper increased.
- Have a learning support **read** the papers.
- For those with **handwriting issues** access to a computer or a writer for the student.
- Assist the student with **exam preparation** by offering pre-exam notes and study techniques.

School Counselor

Approximately 30% of individuals with 22q11.2DS are affected by serious mental health issues. These issues range from depression through to schizophrenia. Using the school counselor to monitor the student for possible early warning signs is one way of ensuring early diagnosis and treatment of mental health issues if they present. Most students will suffer anxiety.

Life Skills

Most government and many non-government schools offer a life skills curriculum. Before deciding that a student should undertake a course based on Life Skills outcomes and content, consideration should be given to other ways of assisting the student to engage with the regular course outcomes. This assistance may include a range of adjustments to teaching, learning and assessment activities.

If the adjustments do not provide a student with enough access to some or all the Stage 4, 5 and Stage 6 outcomes, a decision can be explored for the student to undertake Life Skills outcomes and content. This decision should be made through the collaborative curriculum planning process involving the student and parent/carer and other significant individuals.

An Individualised Education Program is instrumental in assisting a student with learning issues. The IEP generally includes:

- A description of the student’s current skill levels based on formal assessment.
- Measurable and observable goals for improvement in each area of educational need.
- Measurable and observable objectives describing specific skills needed to reach IEP goals. What types of specially designed instruction will be provided.
- When, where, and for how long specially designed instruction will be provided.
- Additional, related services the student will need to support specially designed instruction. Allowances for time away from school due to medical issues.

Adjustments to support the learning for students with disabilities include all actions which increase the capacity of a student to access, participate in and achieve their intended learning goal. Schools need to work with the student, parents and carers to explicitly plan the required support and ensure that this is provided in ways that are consistent with the dynamic and unique features of the school and the student.

Sample IEP Template

Specific Long-Term Learning Targets			
Learning Target 1			
Area:	Social	Success:	Achieved <input type="checkbox"/> Ongoing <input type="checkbox"/>
Target: I am learning to ...		Success Criteria: If I am successful I will be able to ...	
- Speak using an appropriate volume in the classroom and when having a conversation 1:1		- Speak using an appropriate volume in the classroom and when having a conversation 1:1 for 5 consecutive days	

Learning Target 2			
Area:	Social/ behaviour	Success:	Achieved <input type="checkbox"/> Ongoing <input type="checkbox"/>
Target: I am learning to ...		Success Criteria: If I am successful I will be able to ...	
- To speak only when it is appropriate to do so in class		- To speak only when it is appropriate to do so in class 80% of the time on 5 consecutive days.	

Useful Resources:

- 22q Foundation Australia & New Zealand | www.22q.org.au
 The International 22q Foundation | www.22q.org
 Guide to Educating Children with 22q11.2DS | <https://cutlerlandsman.com/>
 22q Family Foundation USA | <https://22qfamilyfoundation.org/what-is-22q/22q-for-teachers>
 NESAs | <https://educationstandards.nsw.edu.au/wps/portal/nesa/k-10/diversity-in-learning/special-education/life-skills>

References:

- The Mind Institute California
- Children’s Hospital of Philadelphia
- Brandeis University/Children’s Hospital of Boston
- Dr Linda Campbell Ph.D
- Childhood Development Institute
- Karen J. Golding-Kushner, Ph.D
- Learning Difficulties Assoc. Texas
- Neil Nicoll, Behavioral Psychologist
- University of Newcastle
- NESAs
- Donna Cutler Landsman