



Great Ormond Street Hospital for Children NHS Trust: Information for Families

22q11 deletion syndrome: learning and education

This information sheet focuses on the learning and education aspects of 22q11 deletion syndrome. For more detailed information about 22q11 deletion syndrome in general, please see our other information sheets.

Introduction

One of the more common impacts of 22q11 deletion is a difficulty with learning and memory that can often hinder a child's academic progress in the classroom. It is thought that around 60 per cent of children with 22q11 deletion will experience some degree of learning difficulty. Following are some suggestions of the common strengths and difficulties associated with 22q11 deletion.

Motor and sensory abilities

Children with 22q11 deletion often have poorly developed muscles when they are younger, which means that some motor milestones may be delayed in these children. They sometimes experience some coordination problems that can persist into adolescence. In addition, they may find it difficult to perform tasks that require dexterity and careful control of movements. We think that children with 22q11 deletion may also struggle to use visual information to guide their actions

so might find it difficult to perform tasks that require spatial awareness.

Attention and memory

Studies have shown that some children with 22q11 deletion are often very good at rote learning and can remember verbal material more effectively if they are repeatedly exposed to it. However, in general, they tend to struggle to hold information in their short-term memory. Children with this condition are often described as having problems with their 'executive functioning', which involves planning, thinking flexibly and understanding more abstract ideas. They may struggle to remember, process and organise information efficiently and this may underlie some characteristic classroom difficulties, for example, in mathematics and reading comprehension.

Intelligence, concept formation and problem-solving

Research into the intelligence of children with 22q11 deletion has suggested that their general IQ scores tend to be below average for their particular age group. However, many different subtests are used to assess intelligence and children with this syndrome often score more highly



in certain areas, for example, on verbal tasks compared with performance-based, abstract tasks. This may help to explain their relative strength in reading and spelling but weakness in mathematics.

While research in this area is limited, it is thought that children with this condition often have difficulties in problem-solving and applying information that they have learned in new situations. In some cases, these children remain 'concrete' in their thinking as they grow older and may find it difficult to think in more abstract ways about ideas and concepts. Older children with these symptoms may sometimes struggle to understand and appreciate humour in everyday situations.

Language skills

It is often observed that children with 22q11 deletion may be slow to develop language and grammar. Their voice quality is, in some cases, described as low-volume and monotonic, although they are usually able to modify the pitch of their voice when asked to do so. Some children may struggle to produce speech spontaneously, finding it difficult to remember the specific words that they require. Children with 22q11 deletion sometimes speak in quite short and simple sentences and they may rely on non-verbal gestures more frequently than would be expected. In some cases, children with 22q11 deletion are slow to use complex grammar, use a limited range of words and remain concrete in their use of speech.

Academic achievement

Children with 22q11 deletion are often able to read fluently and can write and spell relatively well. However, despite being able to read the words, their reading comprehension abilities tend to be quite poor and they often struggle to understand and recall facts that they have read. In addition, they can find it very difficult to copy down text, as this requires coordination and the ability to hold the information in the memory for the short term. Arithmetic tends to be problematic at all ages, with these children sometimes finding it hard to understand mathematics and carry out calculations. In the classroom, children with this condition often remain passive so it is important that teachers be aware of the potential underlying difficulties in their understanding.

Social aspects

It is common for children with 22q11 deletion to sometimes struggle in their interactions with other children and adults, and a lack of facial expressiveness is often observed. Their behaviour tends towards extremes, with the children often appearing over friendly or shy. However, they tend to be affectionate and the majority have no serious behavioural control problems. Social withdrawal is common, but this may be the result of the frustration caused by language difficulties.



Final words

It must be noted that there is a striking variability in the presentation and severity of symptoms in different children with 22q11 deletion. Learning difficulties, if present, can take many different forms and it is important to support each child on the basis of their personal strengths and weaknesses to help them achieve their academic potential. Formal assessment is therefore extremely important to ensure that individual needs are addressed.

Further information

Max Appeal

Tel: 0800 389 1049 (free 24 hour answer phone service)

Website: www.maxappeal.org.uk

VCFS Educational Foundation (US)

Website: www.vcfsef.org

International 22q11 Deletion Syndrome Foundation (US)

Website: www.22q.org

For further information, please contact our clinic coordinator on 020 7405 9200 ext 7922 Monday to Friday 9am to 5pm

Useful numbers

GOSH switchboard	020 7405 9200
Speech and Language Therapy Department	020 7813 8110
Cleft Lip and Palate secretaries	020 7813 8242
Cleft Service fax	020 7813 8279

Notes

Compiled by the 22q11 Deletion Syndrome team in collaboration with the Child and Family Information Group

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www.goshfamilies.nhs.uk

www.childrenfirst.nhs.uk