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PREPARED FOR YOU BY: the 22q FAMILY foundation

Resources:

Educating Children with Velocardiofacial Syndrome (Plural Publishing)

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VCFS Virtual Center
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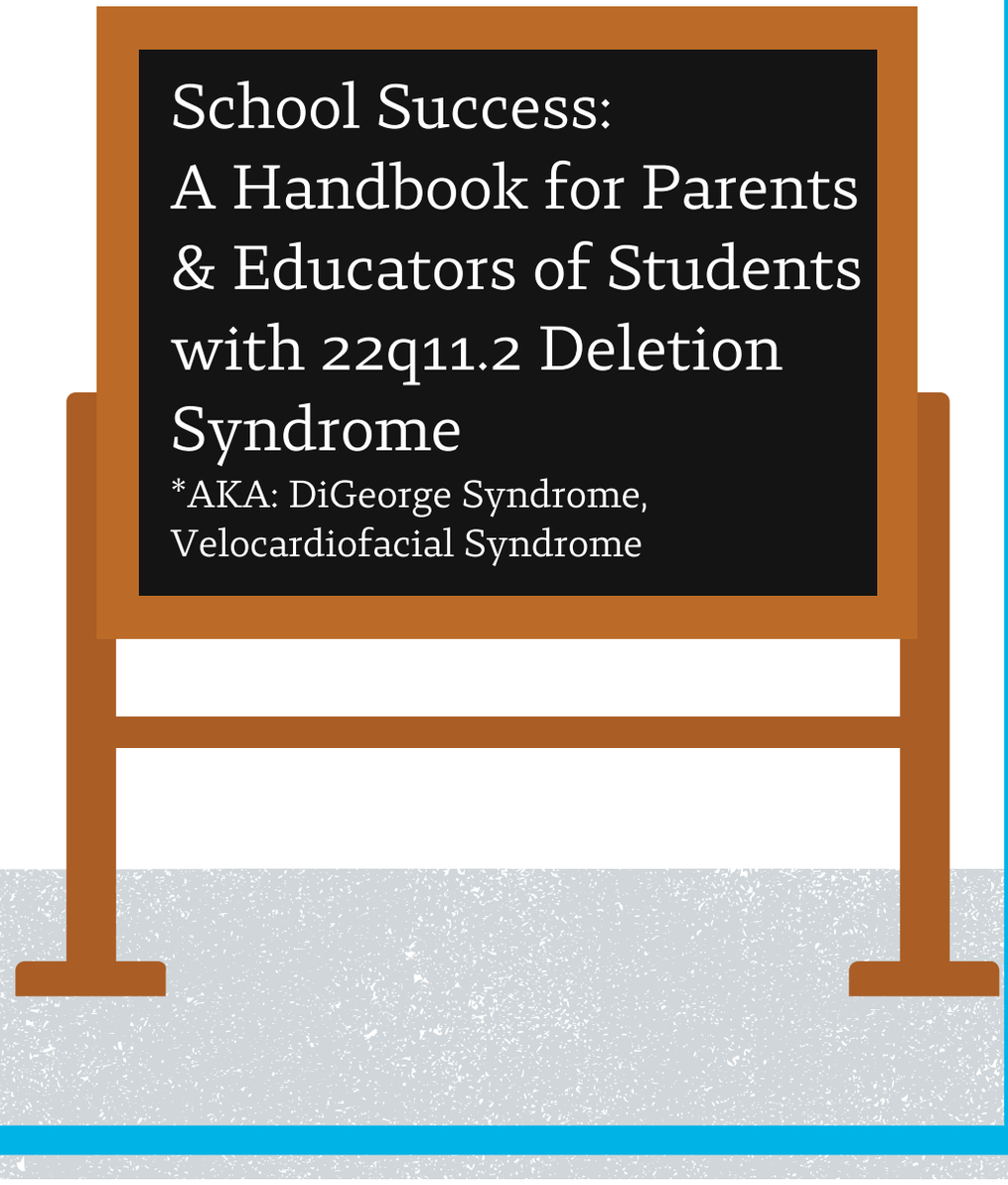

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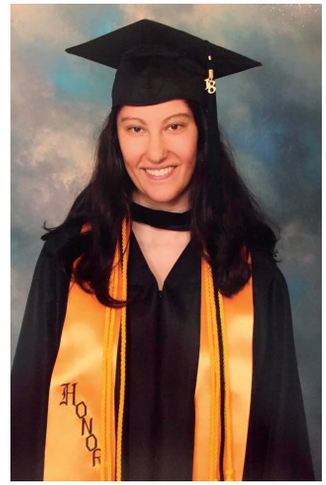
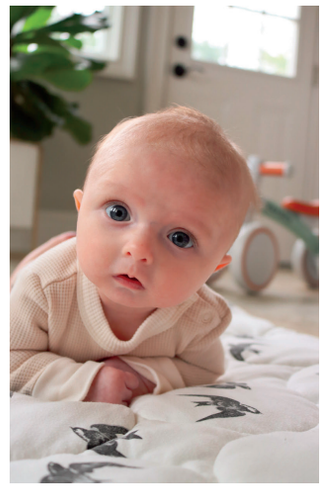








22q11.2 Deletion Syndrome

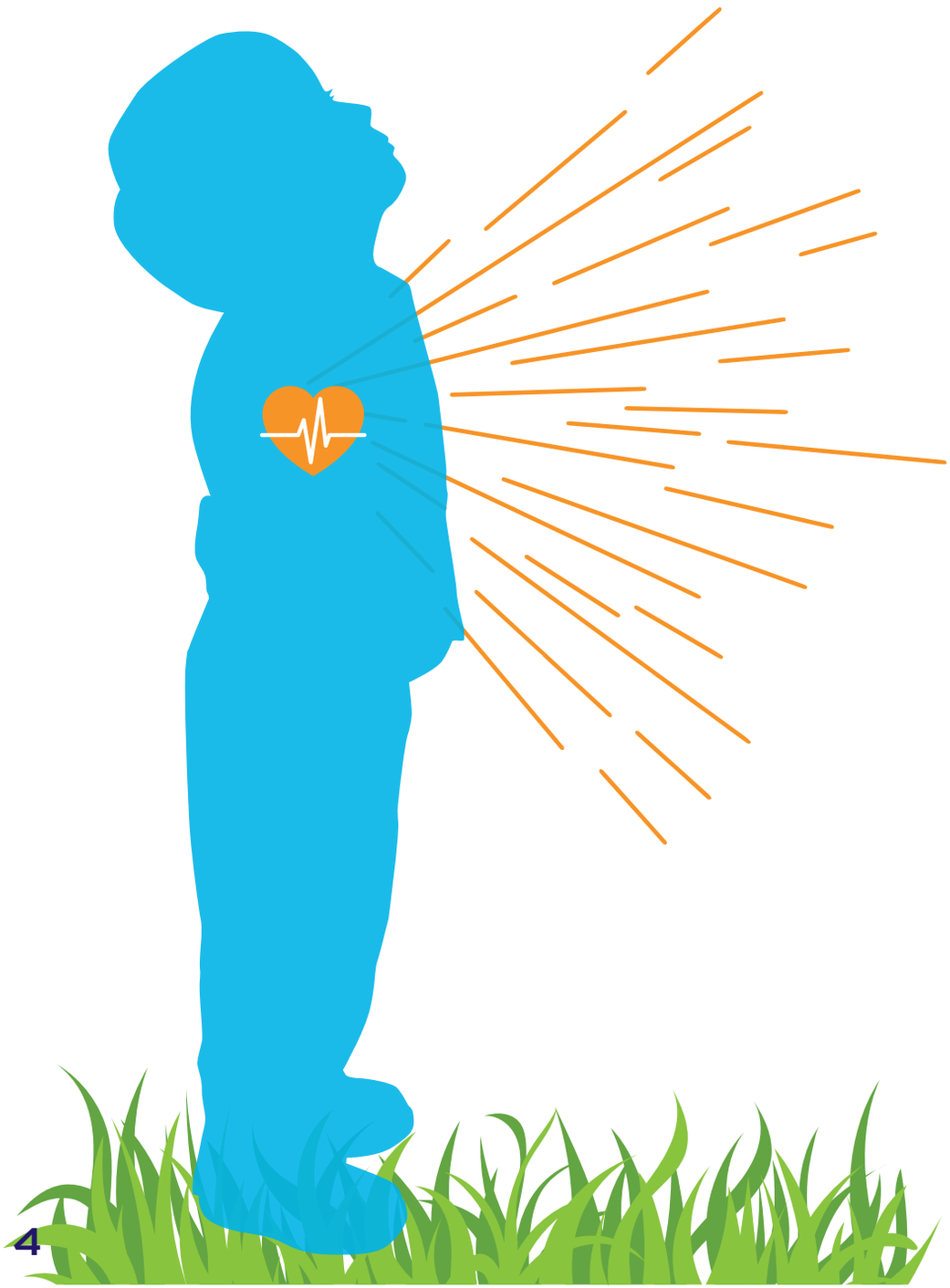
AKA: DiGeorge or Velocardiofacial Syndrome

22q11.2 Deletion Syndrome (22q) is a relatively common genetic condition, often unheard of, caused by a partial deletion of genes on chromosome 22. The range and severity of symptoms can vary widely between affected individuals. This is a neurodevelopmental disorder that typically follows a predictable path. Having behavioral, educational, and family supports may help reduce the impact this condition has on learning.

Major areas of educational impact

- Cognition (including learning, memory, & processing speed)
- Speech & language deficits
- Executive functioning deficits
- Adaptive skill acquisition delays
- Fine & gross motor difficulties
- Low muscle tone & fatigue
- Visual perceptual struggles
- Social skill challenges
- Behavior concerns (ADHD, anxiety & other mental illness)
- Autistic-like features (self-regulation, rigidity, sensory needs & restricted interests)
- Health conditions (causing frequent absences from school)
- Difficulty with self-advocacy

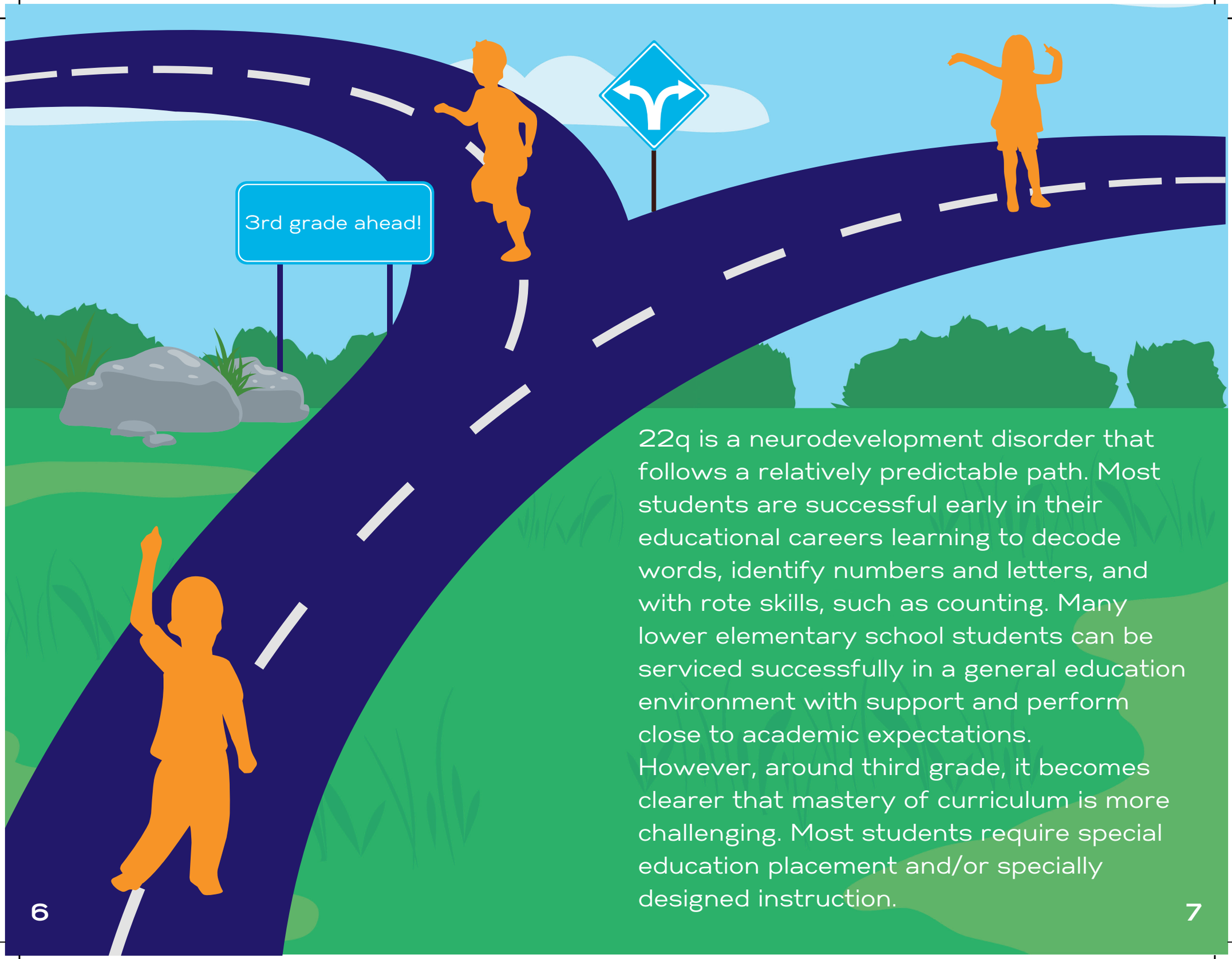
What You Need To Know



Medical conditions impacting classroom performance:

This child may experience more absences due to ongoing medical management including:

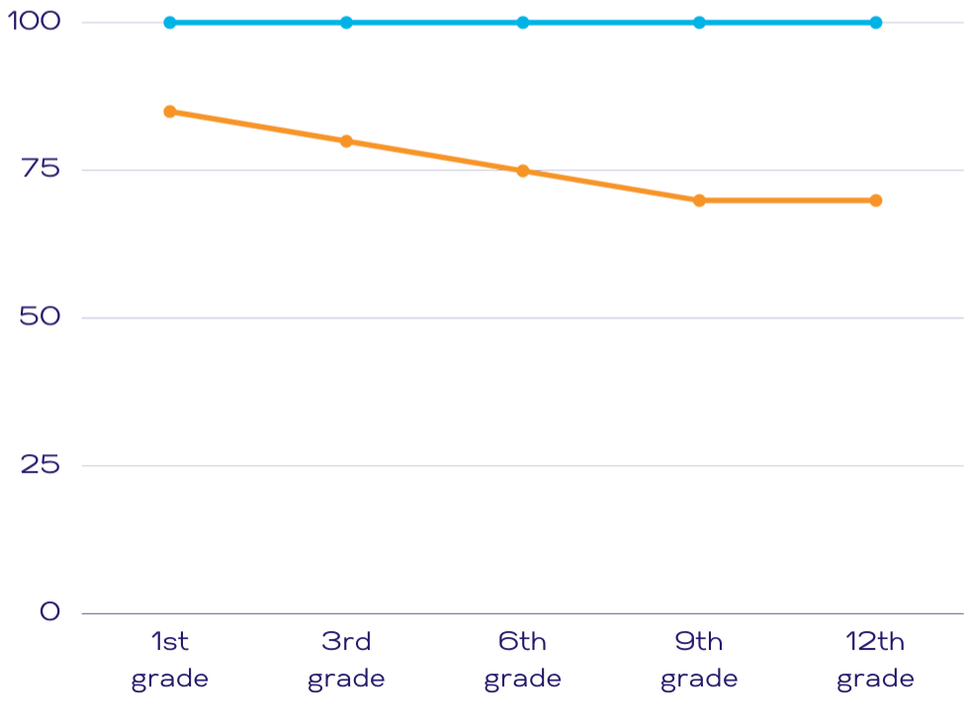
- Heart defects (often requiring surgery and follow up)
- Immune deficiency (frequent infections with prolonged absences)
- Endocrine (growth and metabolic concerns)
- GI (constipation, acid reflux & feeding challenges)
- Vision (visual-perceptual challenges)
- ENT (hearing loss & recurring ear infections)
- Disordered sleep (trouble falling & staying asleep)
- Anxiety (somatic complaints, avoidance of school & perseveration)
- Mental health conditions (increased risk of developing psychosis, mood disorders, OCD, and anxiety that is triggered by stressors)



22q is a neurodevelopment disorder that follows a relatively predictable path. Most students are successful early in their educational careers learning to decode words, identify numbers and letters, and with rote skills, such as counting. Many lower elementary school students can be serviced successfully in a general education environment with support and perform close to academic expectations.

However, around third grade, it becomes clearer that mastery of curriculum is more challenging. Most students require special education placement and/or specially designed instruction.

IQ in 22q11.2 DS individuals (22q) versus neurotypical individuals (NT)



In this population, IQ is not static and may decline over time. Although, in early elementary school scores can be average to low average, by age 18 most young adults are functioning close to the intellectual disability range. This causes a mismatch between expectations and ability that can add a great deal of stress and challenges over time.

It is paramount that schools recognize this and frequently test these students so that the curriculum matches their ability. Schools must also understand that students with 22q need a robust and well thought out transition plan that focuses on functional skills.

Grade specific considerations and challenges:

Preschool & Early Education (PK-2)

- Teachers should not assume that a nonverbal/unintelligible student will not develop language skills. Early speech delay is often due to structural abnormalities. With surgical intervention to correct velopharyngeal deficiency and intensive speech therapy, most students can develop normal speech
- Occupational therapy (fine motor, visual-perceptual, & adaptive skills)
- Physical therapy (gross motor skills & low muscle tone)
- Social skills (isolated play, struggle to initiate interactions, avoidance of eye contact, restricted interests, inability to read nonverbal cues)
- Academic (areas of deficit are typically math & reading comprehension)

Upper Elementary (3-5)

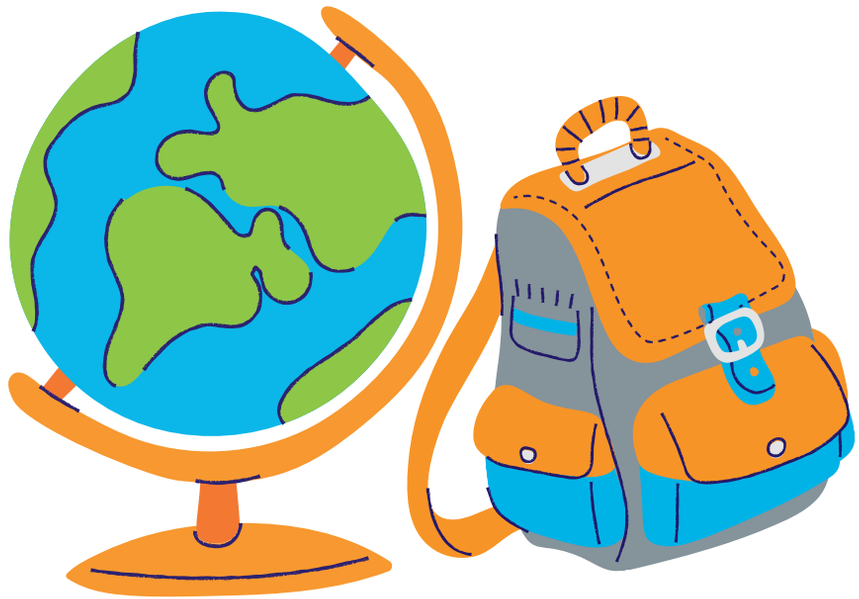
- The school should reassess students at this age level and before entering middle school, as oftentimes there is a decrease in IQ from prior testing
- Most students with 22q need material re-taught in a simplified manner
- Difficulties with executive functioning are common & require targeted interventions.
- Math is an area of concern with profound difficulties grasping concepts of space, time & number
- Rote memorization of math facts can be a strength but application is deficient
- Reading skills are splintered with decoding skills much stronger than comprehension
- Writing can be an area of relative strength, but students struggle with organizing ideas and adding detail
- Reading social cues and understanding others' perspectives can be delayed, so students may benefit from direct social skills training

- Students are more susceptible to bullying as they struggle to navigate friendships and fit in
- Many students become overwhelmed at school during this time and experience increasing anxiety trying to grasp material and follow school expectations
- The school should monitor homework expectations, modify when needed, and work with the family to ensure the student is completing work independently at home
- Many students with 22q do better in a smaller environment for targeted academic support
- Most students with 22q are cooperative, pleasant, and work hard to please. However, they may not be able to master the increasing difficulty of work at this age level
- Language delay becomes more apparent, and students often require therapy to address higher-level thinking skills and pragmatics

Middle School (6-8)

- Students will need additional support in mathematics and reading comprehension
- Executive functioning is an area of deficit.
- Students will need help with planning and organization
- Language deficits will make following complex directions particularly challenging
- Test taking skills are extremely variable, so flexibility in grading and opportunities to retake tests is highly recommended
- Social skill deficits and attention difficulties put students at higher risk for bullying and loneliness
- Friendship opportunities may need to be orchestrated and students may need counseling support
- This syndrome is the strongest known genetic risk factor for schizophrenia. Research shows that perceived stressors, over time, can trigger an acute mental health episode. For this reason, it is vital that staff strive to minimize stressors by maintaining a flexible and supportive approach to learning.

- Students will need support communicating the nuances of assignments to parents and tutors
- Assisted technology, such as calculators and word processing programs are encouraged
- Written instructions are useful in guiding students through assignments



High School (9-12)

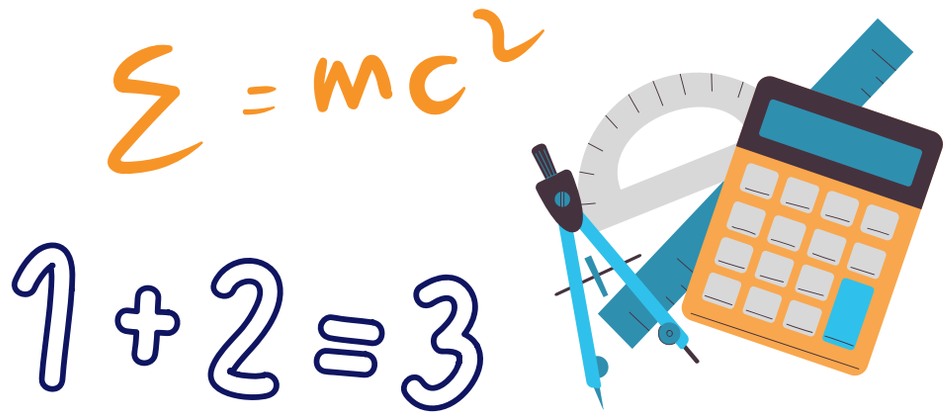
- By age 18, IQ scores of students with 22q are often at the borderline range with a standard score of around 70.
- Many students with 22q will benefit from remaining with the school system until age 21, so graduation at age 18 should be carefully assessed
- It is extremely important to plan for community support post high school and to involve the appropriate agencies in the IEP process
- Parents should be connected with resources in the community to link them with programming, trainings and supports to ensure a successful transition.
- There is a wide variability in this syndrome, so realistic goal setting is critical at this time. Many students find that working in smaller classes with less rigorous curriculum a better fit
- Students will likely need tutoring and additional academic support
- Students will need a carefully orchestrated transition plan that includes: vocational assessment, job shadowing, job placement, and vocational training
- A functional assessment, such as the Vineland, should be given to determine the need for instruction in independent living skills
- Transition plans can include post-secondary classes and job training
- Mental health conditions are very prevalent with this syndrome, so staff should adopt a flexible and nurturing attitude to reduce stress and anxiety for this student
- Test taking skills are extremely variable, so flexibility in grading and opportunities to retake tests is highly recommended

Key Points for Educators by Subject

Math

Individuals with 22q deletion syndrome may have significant visuospatial deficits, diminished math attainment, and executive dysfunction. Math learning difficulties in 22q deletion include difficulties in understanding and representing quantities and in accessing the numerical meaning from symbolic digits

- Deficits in the following areas may contribute to difficulty in math including: nonverbal processing, visual-spatial skills, complex verbal memory, attention, working memory, and visual-spatial memory
- Programs that include direct instruction and multiple opportunities for practice work better than a discovery or spiraling curriculum
- Encourage students to adopt one approach to solve a problem and practice that technique to mastery
- Minimize the number of problems per page and provide line/graph paper to assist with number placement



- Emphasize real world math applications such as budgeting, time, money, and number sense rather than complex calculation algorithms. Allow calculator use for multi-step calculations
- Provide a template for complex or multistep problems; break down the steps
- Focus on procedural strategies as fact retrieval can be stronger than math application skills
- Emphasize word problems as they may be a significant area of weakness

English Language Arts

Although students with 22q often decode words close to grade level, they typically have much lower comprehension skills

- Emphasize strategies for comprehension of text including: citing evidence for answers and using approaches to assist in working memory deficits
- Select non-fiction texts to improve general knowledge and provide a real world basis for understanding
- Provide accommodations to assist with tracking and visual fatigue
- Allow students the use of templates and graphic organizers
- Provide notes to address motor coordination and memory difficulties
- Allow students to use computers and/or technology to improve their written work

Communication: Speech, Receptive and Expressive Language, and Social Pragmatics

Speech and language development is delayed in most children with 22q. This is typically due to structural abnormalities such as a submucosal cleft palate and velopharyngeal deficiency (VPD)

- VPD can cause hypernasal speech, severe articulation issues, and a delay of speech development
- Remediation of VPD often requires very specific speech therapy and/or surgical management
- Articulation disorders are common and are usually caused by compensatory errors. A small number of students with 22q may present with dysarthria (weakness of oral muscles) or apraxia. It is important to have a highly trained clinician work with a student with 22q as the speech disorder is complex
- Slow vocabulary growth and difficulty in forming complex sentences is also common

Communication: Speech, Receptive and Expressive Language, and Social Pragmatics continued...

- Older children show delays in higher level thinking skills including: inferencing, cause and effect, and problem solving
- Many students struggle with pragmatic language, reciprocal conversation, and reading social cues
- Students may have poor skills at self-advocacy and difficulty expressing themselves especially in perceived stressful situations

Behavioral Concerns

Most students with 22q strive hard to succeed; however, learning challenges may cause work avoidance and over-dependence on others to complete tasks. In addition, high anxiety may cause students to avoid risk taking and self-advocacy.

- Social withdrawal
- Avoidance of tasks when overwhelmed or frustrated
- Poor self-advocacy skills
- Overreaction to minor situations
- Perseveration (getting stuck on one idea/feeling/thought)
- Difficulty shifting from one activity to another
- Tendency to get distracted easily
- Anxiety, often with somatic complaints
- Emotional breakdowns at home around homework and school issues

Recommendations for Behavioral Concerns

- Administer a functional behavioral assessment for behaviors that impact educational success
- Consider sensory breaks, behavioral reward programs, minimizing demands, removing from a highly stimulating environment, assigning a staff mentor, shortening school day
- Teach coping skills using direct instruction and emotional regulation strategies
- Provide social skills training
- Pair student with peer mentor
- Offer counseling
- Provide structure and routine to help reduce anxiety

General Learning Recommendations (for all ages and stages of 22q individuals):

- Small class size for weak academic areas
- Preferential seating
- Extended time for assignments and tests
- Notes provided
- Visual calendar/schedule
- Assignment notebook support
- Regular communication with home
- Opportunities to retake tests and improve grade
- Modified work/homework if necessary
- Emphasis on real world applications
- Life skills instruction
- Frequent check-ins to monitor progress
- Pre-teaching and re-teaching to support learning
- Sensory regulation breaks
- Direct instruction with lots of repetition
- Task broken into smaller steps