SUPPORTIVE GUIDANCE FOR XYY SYNDROME





Please note: Each XYY male is unique and the following strategies, tools and tips are to be used as a guide and may not apply to each individual XYY male.

XYY SYNDROME



- What is XYY Syndrome and how a diagnosis is made
- Therapists utilised for XYY Syndrome
- Specialist support Occupational Therapist
- Associated traits and characteristics
- Understanding XYY Syndrome
- XYY and Executive Functioning
- How an Educator can help and support XYY
- Communication between the teacher, EA, and parent in relation to the needs of each individual child.
- Sharing our experiences as a family living and caring for a child with XYY Syndrome

WHAT IS XYY SYNDROME AND HOW A DIAGNOSIS IS MADE



- Only males are born with XYY Syndrome
- In males their genetic make-up consists of one X chromosome and one Y chromosome (XY)
- XYY Syndrome is a genetic condition caused by a random split in the cells which creates an extra copy of the Y Chromosome (XYY)
- Males with XYY syndrome have 47 chromosomes because of the extra Y chromosome, where the average male has only 46 Chromosomes
- Diagnosis can only be confirmed by a genetic blood test

THERAPISTS UTILISED FOR XYY SYNDROME

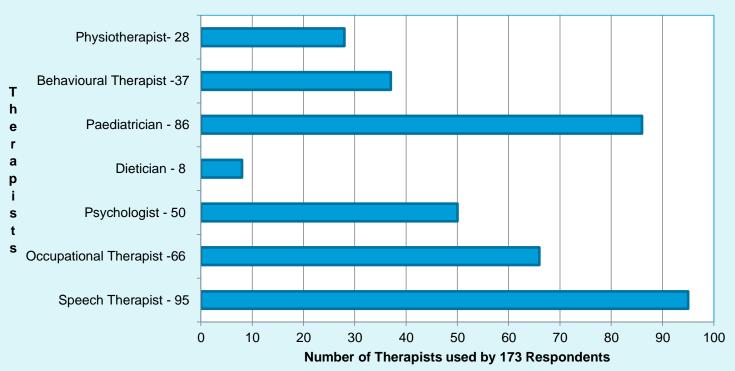


GP & Geneticist

Neurologist (Brain)

Podiatrist (Feet)





Pulmonologist (Chest)

Psychiatrist

Social Communication Therapy

SPECIALIST SUPPORT - Occupational Therapist:



GROSS-MOTOR:

FINE-MOTOR:

DAILY LIVING:

Focus Areas:

Motor, Core, Balance

Activity:

- Obstacle course
- Scooter & balance boards
- Stack of pillows
- Island hopping
- ❖ Fit ball
- Hopscotch
- Heavy work activities
- Climbing
- ❖ Bike riding

Focus Areas:

Hand strengthening, Bilateral co-ordination

Activity:

- Tug of war
- Play dough
- Rolling pin
- Catch and throw
- Lacing/threading beads
- Hand clapping rhymes
- Pegs
- Tongs/tweezers

Focus Areas:

Putting shoes on, Tying laces, Brush teeth, Personal hygiene,

Activity:

- Threading
- Cutting
- Spreading
- Rolling
- Posting
- Peg games
- Lego
- Putting on and tying shoes

ASSOCIATED TRAITS AND CHARACTERISTICS



Emotional dysregulation

Executive Functioning

Speech and language delay

Impulse

control

Behavioural difficulties

Low muscle tone

More than above average height

Underdeveloped social skills

Sensory Processing

Disorder

Inattention

XYY Syndrome Association of Australia Inc.

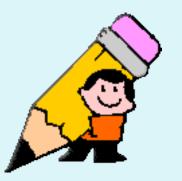




Coordination









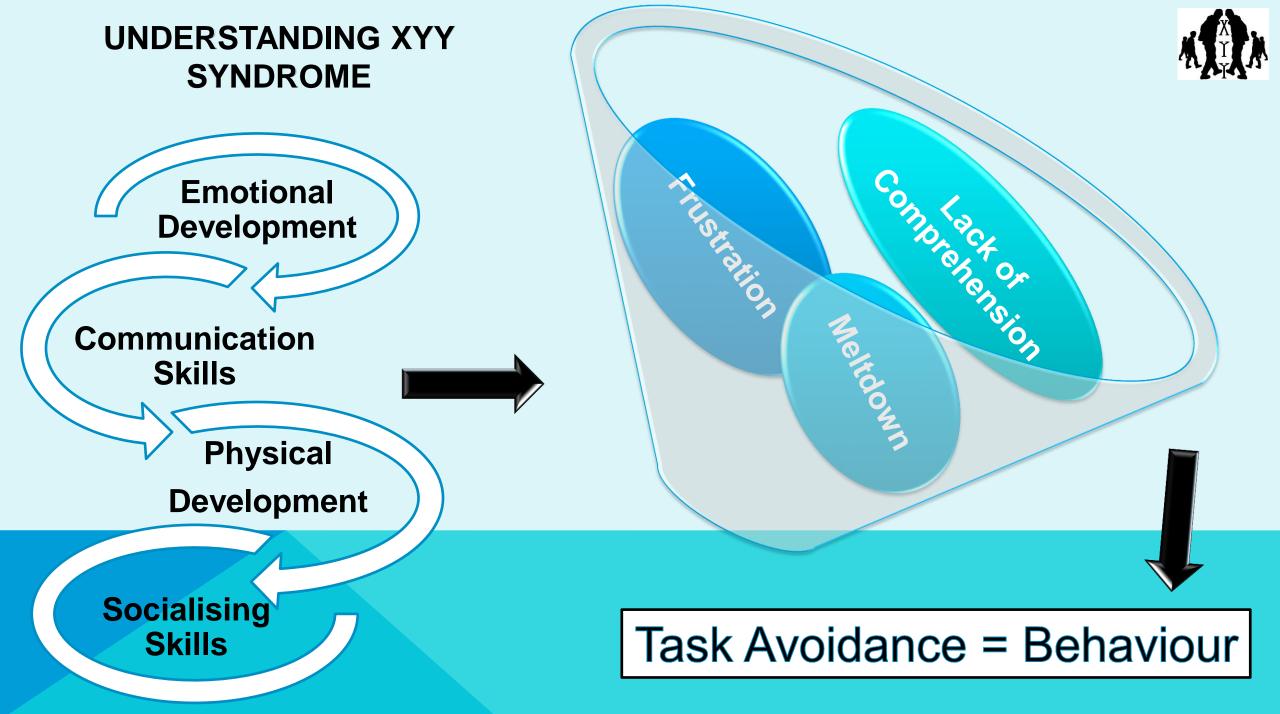
Easily tired

Low muscle tone

Less range



Muscles work harder



XYY AND EXECUTIVE FUNCTIONING



What is Executive functioning?

Skills:

- Planning and implementing
- Regulating behaviour
- Impulse control
- Attention
- Organising
- Working memory

Strategies:

- Visual supports
- Supporting emotions
- Creating steps to support tasks
- Supporting changes & transitions

EDUCATOR STRATEGIES TO SUPPORT XYY



- Trust, building a relationship
- ❖ 1:1 support
- Being aware of cues/triggers
- Set clear rules and boundaries
- Flexible learning plans
- Scaffolding tasks
- Visual aides
- Using timers for specific tasks
- Modelling appropriate behaviour
- Use rewards of child's interest or positive reinforcement
- Allow processing time less words is best



Communication training and behaviour therapy will help males with XYY Syndrome learn to socialise more successfully.

STRATEGIES WITHIN A CLASSROOM



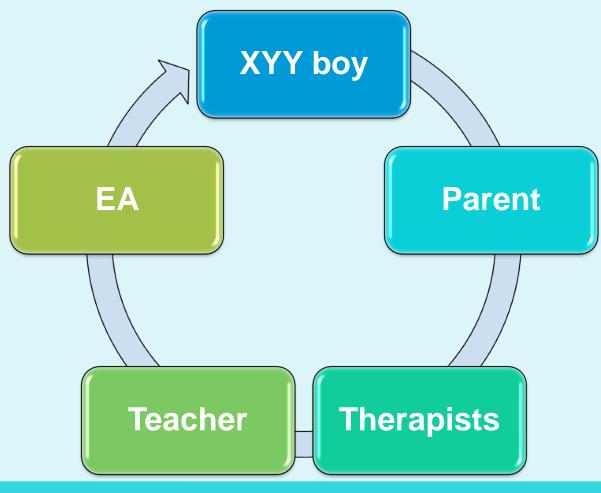
- Pick your battles
- Retain trust
- Scaffolding tasks comprehension
- ❖ Now / Then
- Flexible routines
- Visual charts, movement to goal
- Allowing independence with direction to stay on task
- Social stories appropriate behaviour
- Guidance needed for social interactions

Recommended courses:

- \$1,2,3 Emotional coaching
- **❖** PATHS
- Positive Partnerships

COMMUNICATION





NOTE:

Consistency in communication is needed between Teacher and EA towards student

SHARING OUR EXPERIENCES WITH XYY SYNDROME



What home life looks like: Our son is 8 years old

- ❖ Tight routine during school week
- Maintain a structured routine including weekends and school holidays
- Therapy includes Speech, Paediatrician, Behavioural Therapist, Developmental Therapist, Occupational Therapist, in house support and social groups during school holidays
- Other Therapists Genetics, Psychologist, Physiotherapist, Social Worker, Local Area Co-ordinator
- CONSTANT supervision

SHARING OUR EXPERIENCES WITH XYY SYNDROME



- Fixated on activities/people
- Impulse control
- Finds it hard to stay on task, unless it's of interest
- Emotional response, outbursts, throws objects
- * Restless going to bed, inability to wind down which can impact next day

STRATEGIES:

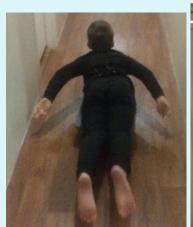
- Short burst activities
- Timer and visual aides
- ❖ 1:1 sports i.e. horse riding and rock climbing, can be lost in group sports

Concerns for child protection and road safety

Activities & Resources used to support XYY Syndrome



















XYY Syndrome Association of Australia Inc.

XYY SYNDROME IS ALSO COMMONLY DIAGNOSED ALONGSIDE:



- Autism
- Attention-deficit/hyperactivity disorder (ADD/ADHD)
- Obsessive compulsive disorder (OCD)
- Oppositional defiant disorder (ODD)
- Dyslexia
- ❖ Asthma
- Hypotonia

- Hypermobility
- Apraxia
- Dysarthria
- Anxiety
- Epilepsy
- Tourette's Syndrome
- Global Developmental Delay (GDD)
- Sensory Processing Disorder

XYY SYNDROME IS INVISIBLE
NOT ALL DIFFERENCES ARE NOTICEABLE



XYY SYNDROME ASSOCIATION OF AUSTRALIA INC.



Mission Statement

- Creating awareness for XYY Syndrome by obtaining and providing the latest research for XYY families and the community.
- Networking with government services, medical specialists, general practitioners and educators to create better understanding for XYY Syndrome.
- Rare Syndrome recognition for XYY Syndrome within State and Federal Government and educational systems.

Website: xyyaustralia.org

Facebook:

XYY Syndrome Association of Australia Inc.

XYY Syndrome Support Page Australia

THIS MATERIAL IS THE PROPERTY OF THE XYY SYNDROME ASSOCIATION OF AUSTRALIA INC.

XYY Syndrome Association of Australia Inc. © Copyright 2018 Author - Amber Gilkes

All Rights Reserved. All contents of this document are copyright and may not be reproduced or used without the permission of Amber Gilkes, XYY Syndrome Association of Australia Inc.

Disclaimer

The information and resources used in this guidance pack are to be used for awareness, support and educational purposes only.

They should not be used as a substitute for seeking professional advice in the diagnosis, treatment and management of XYY Syndrome.

Permission:

- Personal use is permitted.
- Usage is also granted to share for educational purposes.
- Commercial use of any sort is expressly prohibited.

Please contact xyyaustralia@gmail.com should you require permission to reproduce any of the contents