



Amanda Miller

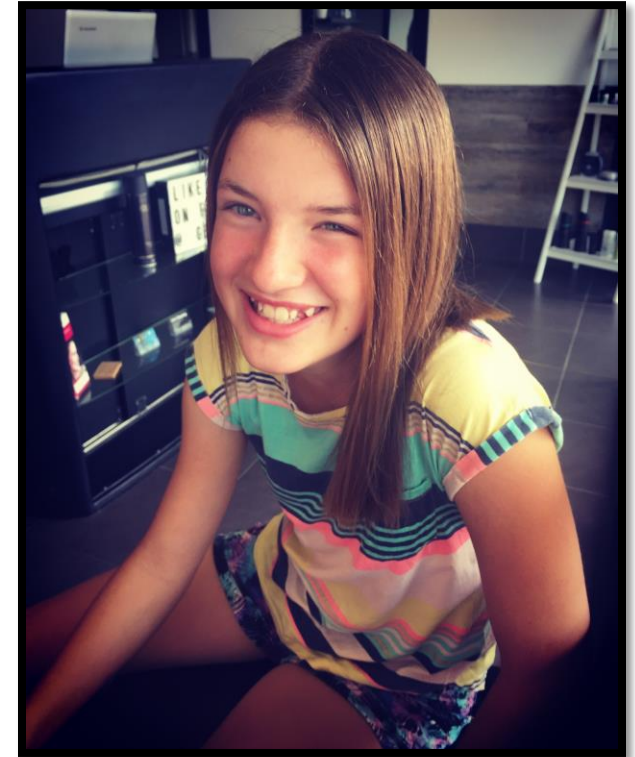
Educational implications for Trisomy X Girls and Women

*4th May 2018
Genetic Alliance Australia*

3rd Annual conference

08. 11. 2015

Personal Introduction



My daughter, Grace has Trisomy X syndrome

Age: 13 years old

Year: 8

Triple X & Trisomy X Support Group, Australia

Why did I start the Support Group on 20th September 2013?



115

*SUPPORT OTHERS

*ADVOCACY

*SHARE INFORMATION

*"It is in our genes to understand the universe if we can,
to keep trying even if we cannot and to be
enchanted by the act of learning all the way."*

Sometimes, real superheroes live in the hearts of
small children fighting big battles.



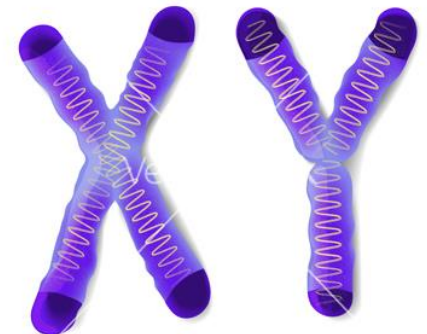
There is no “I” in TEAM!



TRISOMY X Syndrome

- » My Teacher thinks that I'm just a late talker...
I'M NOT!
- » My Dad worries that I may not be intelligent...
BUT I AM!
- » My Doctor wonders if I am Autistic...
I'M NOT!
- » My Mum is afraid that I have multiple medical problems...
I COULD HAVE...

X and Y Chromosomal variations may cause Learning disabilities, Speech and Motor delays, Central Auditory Processing Disorder (CAPD) and Reading dysfunction.



Early Intervention - Preschool

Early intervention services are recommended for infants and children diagnosed with Trisomy X.

Experts advise:

- *Developmental assessment – 4 months old
- *Language and speech assessment - 12 months
- *Pre-reading assessment – 3 to 5 years
- *Language, social and motor development assessment
- *Social functioning test – 5 years of age
- *Multi-disciplinary assessment
- *Educational and learning needs assessment

Early Intervention



Evidence suggests that affected children are greatly responsive to early intervention services and treatment. Such services can include Speech therapy, Occupational therapy, Physical therapy, Developmental therapy and Counselling.

Where to begin at Primary school



Meet with
the
Teacher

Explain your
daughter's
strengths and
learning styles

Keep in
touch on
a regular
basis

Constant communication between home and school is very important

EDUCATIONAL PERSONALISED PLAN (P.P.)

Ask your school how to get a PP put into place for your daughter.

Learning Support or Special Education Teachers work collaboratively with school principals, staff, students and parents to develop an appropriate individual and personalised plan for each student with a disability.

*It is recommended that a PP is negotiated and updated
at least once a year.*



Assistive technology

- Text to speech
- Voice recognition
- Digital recorders
- Reading pens
- iPads & tablets
- Word prediction software
- Audio books



Suggested modifications to include in a PP

- Reduce visual overload
- Different type of assessment
- Shorter school day
- Providing extra time
- Short breaks and chill out spaces
- Visual aides
- Mnemonics
- Reduced homework



Example of a PP

CLASS: 3F

Harriet has (surface) DYSLEXIA, DYSCALCULIA and ANXIETYATTENTION TEACHER

PLEASE READ

(Report on file)

THIS AFFECTS;

- reading
- Writing
- spelling
- mathematics
- processing speed
- Working memory
- Harriet is very anxious especially with change such as relief teachers. She likes to know what is coming next.

PLEASE SEE BELOW FOR CLASSROOM ACCOMMODATIONS

CLASSROOM ACCOMMODATIONS:

- Do not keep Harriet in to complete work
- Sitting closer to the board will help.
- Do not get Harriet to redo written work
- Please reward effort not outcome
- Do not make Harriet read out loud to the class unless she chooses to.
- Please do not expect Harriet to copy large amounts of written work/ use the IPAD to take a photo
- Provide notes to highlight where possible
- Use positive reinforcement and encouragement
- Modify work/ reduced amount/ use of scribe/ reader
- Allow use of assistive technology where applicable
- Allow use of word banks and maths aids, esp manipulatives
- Break down instructions into steps and ensure she understands
- Prepare her for what is coming next.
- Give her more time
- She learns best with concrete apparatus and visually
- She has an ILP for Maths and Spelling
- She only needs to wear her glasses 3 days a week- Mon, Wed, Fri
- She has an IPAD to help her.

Harriet Loves....

- ANIMALS
- ART
- MUSIC
- WORKING WITH FRIENDS WHO CAN HELP HER

SHE IS A SMART CHILD WHO HAS A SPECIFIC LEARNING DIFFERENCE.
SHE IS TRYING HER VERY BEST AND HAS TO WORK HARDER THAN MOST.

**SHE DOES NOT LIKE MOVIES (CHECK BEFORE
SHOWING THEM) (MUM IS IN SCHOOL)**

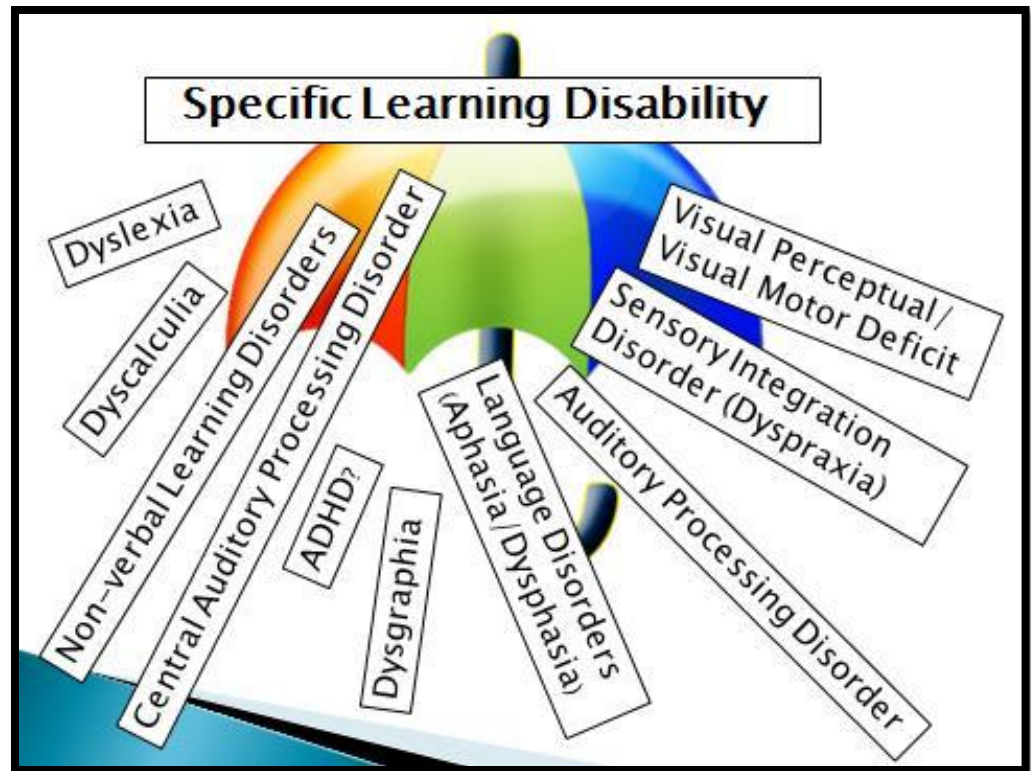
Language based learning difficulties

Girls with Trisomy X have an increased frequency of language-based learning disabilities including reading deficiencies such as dyslexia, reading comprehension deficits and/or reading fluency issues in conjunction with other language-based disabilities.

**Developmental Dyspraxia*

**Motor planning skills:*

- gross & fine motor*
- speech and language*
- executive function*



Speech therapy

What language activities promote success for our girls?



1. Importance of joint book reading
2. Model how to sharpen comprehension skills
3. Have your daughter retell a story
4. Teach how to increase your child's awareness of print
5. Demonstrate strategies to teach letters and their corresponding sounds
6. Model literacy activities at home ourselves

Expressive Language Delay

Expressive language delay impacts our girls in all aspects of learning

VISUAL & “HANDS ON” TEACHING APPROACH
SUIT OUR GIRLS PERFECTLY!

- *Difficulty conveying or expressing information in speech, writing, sign language or gesture;
- *Some children are late in reaching typical language milestones in the first three years, may catch up to their peers;
- *These children are commonly referred to as ‘late-talkers.’





Encourage your daughter's Teacher to:

- *Remain positive;
- *Ensure that work is achievable;
- *Modify class work;
- *Present instructions in 1 to 2 steps ONLY;
- *Repeat instructions and check understanding;
 - *Re-word the verbal information often;
 - *Ask her to repeat the given instructions;
- *Don't TELL her but SHOW and TELL her when giving verbal instructions.



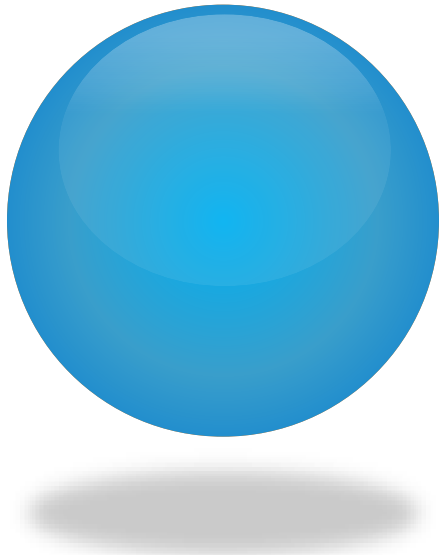
Example of a
'Narrative
scaffold'

Narrative Scaffold	
Title: _____	(every word begins with a capital letter)
Orientation (introduction):	
Who? _____	
When? _____	
Where? _____	
Complication (problem):	
What happened? Why?	

Series of Events:	
What happened next?	
1. _____	
2. _____	
3. _____	
Resolution	
How is the problem solved?	

Coda	
How does the story end?	

ATTENTION AND CONCENTRATION

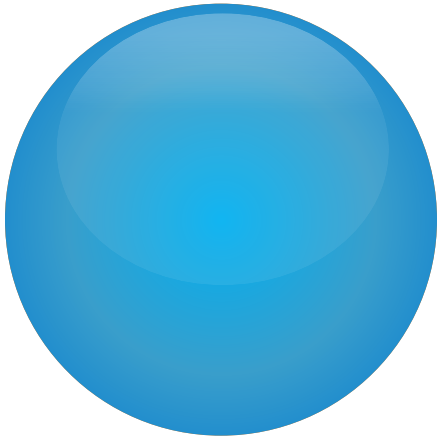


“Girls with Triple X have particular difficulties concentrating and paying attention. Attention may wander and they may have more difficulties than expected seeing tasks through to a conclusion.”

(Tartaglia, 2010)

ATTENTION TO TASKS AT HAND

POOR WORKING MEMORY

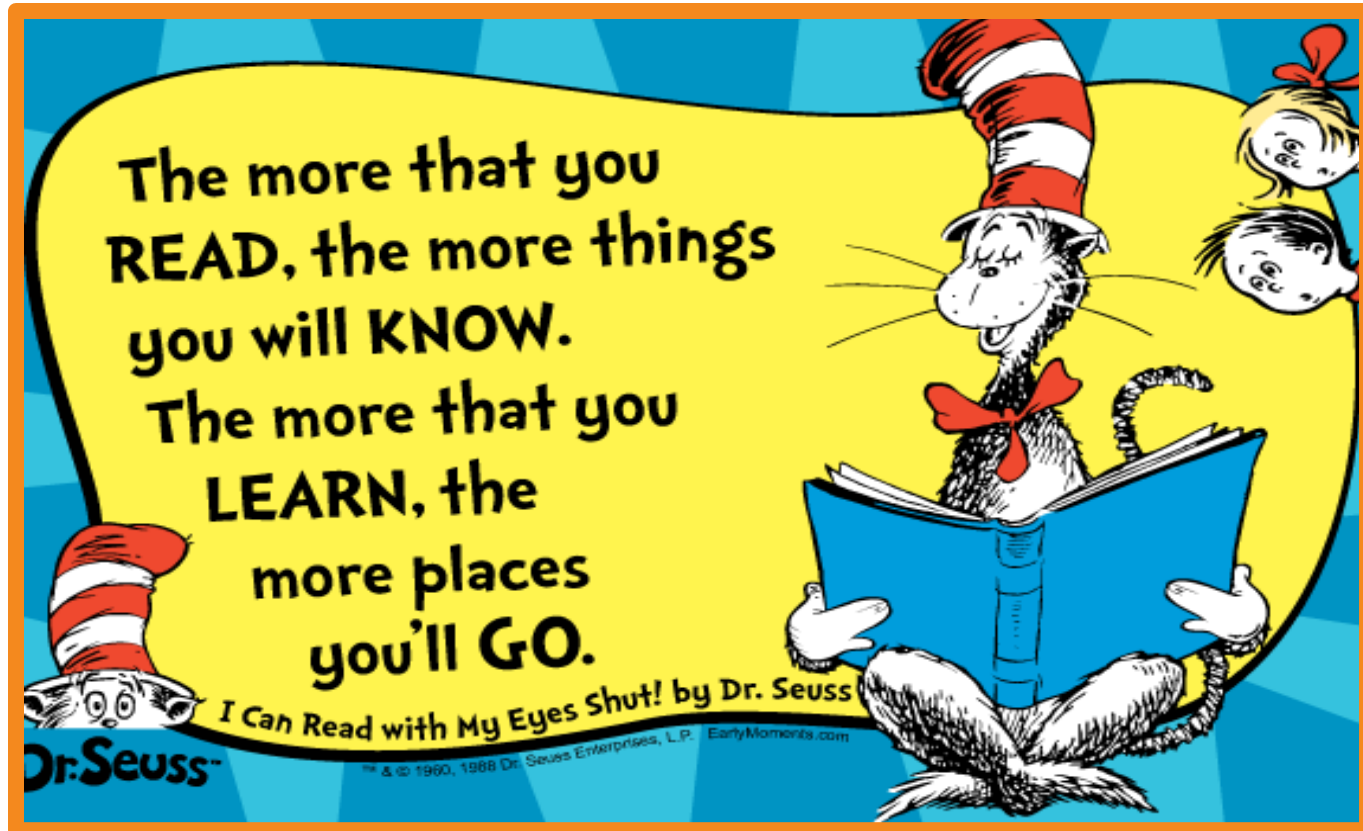


“Girls with Triple X also often have difficulty remembering what they have learned recently and many need information repeated more times to fix it in their memory.”

(Triple X group, 2006)



Knowledge is power



Genes that influence children's reading skills also affect their maths

Study suggests that half of the genes that affect 12-year-olds' literacy also play a role in their abilities in mathematics



▲ Genes linked to both numeracy and literacy may affect brain development and function. Photograph: Christopher Furlong/Getty Images

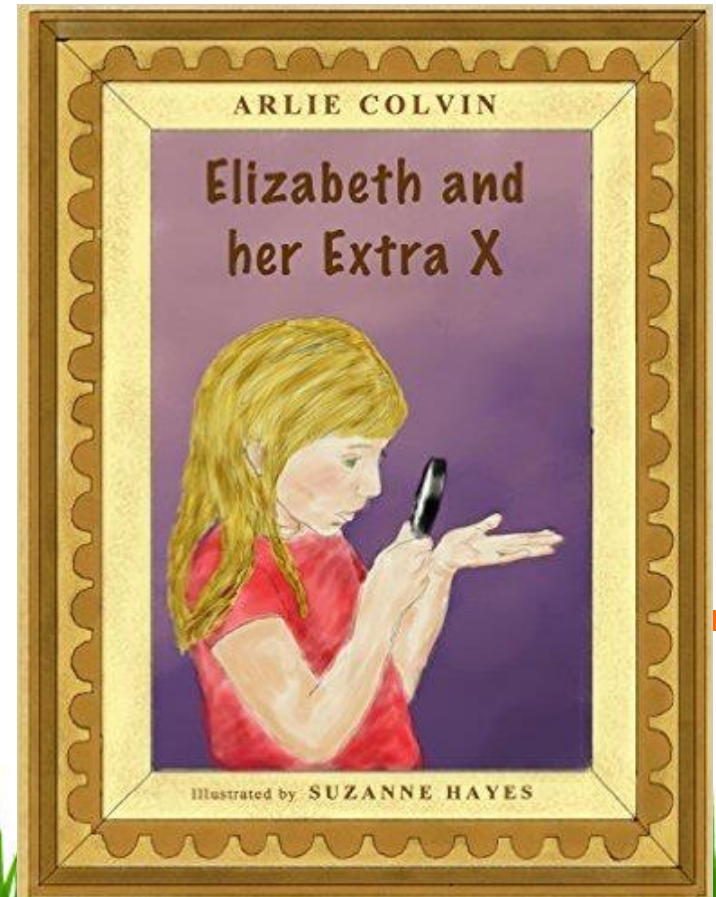
Many of the genes that affect how well a child can read at secondary school have an impact on their maths skills too, researchers say.

Writing in the journal [Nature Communications](#), the authors explain that understanding how genes affect children's abilities "increases our chances of developing effective learning environments that will help individuals attain the highest level of literacy and numeracy, increasingly important skills in the modern world".

“ELIZABETH AND HER EXTRA X” BOOK

Elizabeth and her Extra X is a children's book for kids with Triple X or Trisomy X syndrome (47, XXX). This book helps children and adolescents with Triple X understand their condition.

GREAT
RESOURCE
FOR OUR
GIRLS!



Quotation for our Trisomy X girls



Tired of trying to cram
her sparkly **star-shaped** self
into society's beige **square** holes,
she chose to embrace her **ridiculous**,
awesomeness and shine like
the amazing **supernova**
she was **meant** to be...



Facebook group name:

Trisomy X / Triple X Support Group Australia

Facebook group address:

<https://www.facebook.com/groups/TrXAUS/>

Email address:

amandamiller@iprimus.com.au

Thank you to the many friends present here today that I have shared similar experiences with and have offered me advice on this journey.

Please visit our Facebook page and continue to be a great ADVOCATE for your daughter!

