

# Education and 22q11.2 DS

## A parental perspective

Maria Kamper - 2019

# My Family



# Experience

- 2004 we received the 22q11.2DS diagnosis – Charli was 4 ½ (this took 3 paediatricians)
- Immediately purchased the Educating Children with VCFS book and gave to school she was going to attend - expecting the school read the book and make provisions for our child . **You as a parent should buy and read the book/s and make notes for your teachers** <https://cutlerlandsman.com/>
- When our daughter was 7 she was placed in a special needs class (our worst mistake – it's an individual choice)
- Over the years we have developed tools that assist the school with the help of other families and the foundation
- Taught our daughter to self advocate
  - Ask questions when she doesn't understand
  - Ask for extra time
  - Talk to the counsellor when feeling anxious

# Charli now!

- Charli is 20 years old completed Year 12 - Life Skills
- Charli works 20-30 hours per week at McDonalds
- Charli has a drivers licence
- Money is a problem for Charli – we assist in budgeting
- Charli is socially 3 years behind her peers
- Charli suffers Anxiety and OCD
- Charli is relatively social – more-so with older people and little children





# What I have found doesn't work

- ❖ Not telling the school about your child's diagnosis
  - ❖ It's not labelling it's helping those who work with her to understand what appears to be an invisible condition
- ❖ Giving teachers big books and binders of information to read about 22q
  - ❖ **You as the parent need to read the books and use them as a guide for your teachers.**
- ❖ Expecting the teacher to understand or research 22q
  - ❖ They have a class full of kids and many with extra needs
- ❖ Having unrealistic academic expectations – even in the general population not everyone can be doctors or scientists!
- ❖ Thinking the information you supply one teacher is shown to all teachers
- ❖ That it's going to be easy – even if you have a great teacher



# Siblings – the forgotten ones!

- It's important that all the family understand the needs of your 22q child.
- Charli's younger brothers wondered why she didn't have to do the same work
  - Why were they pushed harder
  - Why does she get so much attention
  - Why she was loved more – in their minds



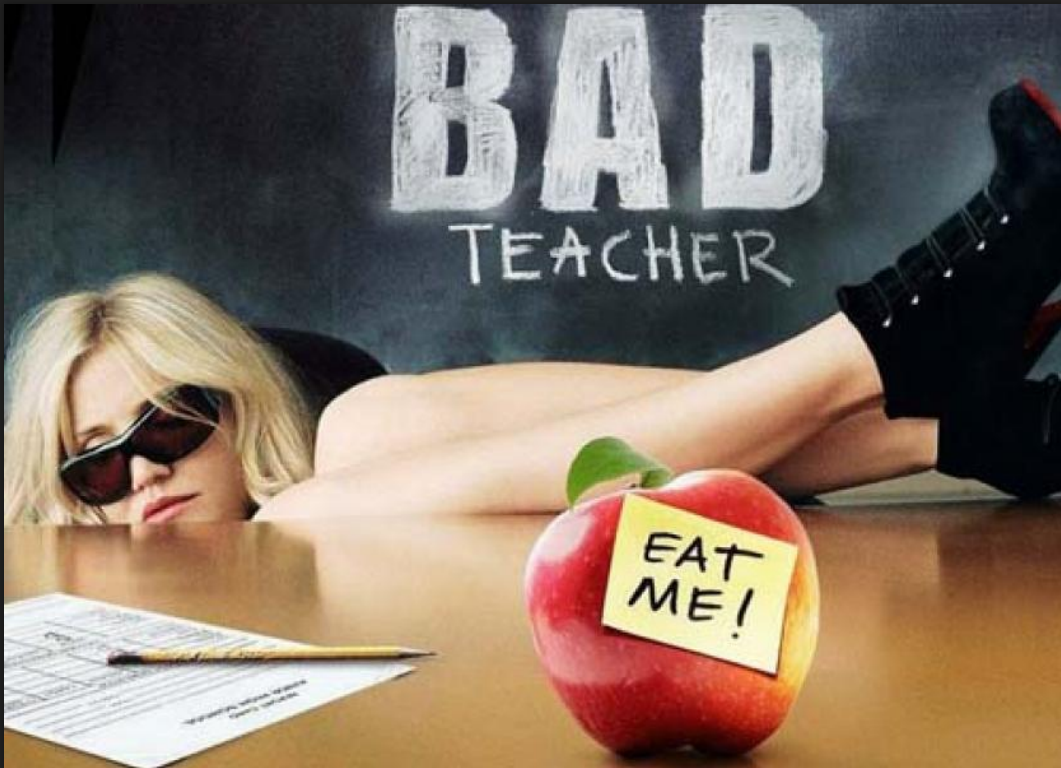
# What we found useful



Work with  
your school  
as a team  
and if it  
doesn't work  
change it



# Not all teachers are as helpful as we would like – it's a lack of understanding



Educate  
them about  
your child  
\*\* Help me to  
help you to  
help me \*\*



# Working with the school to help them understand your child

## One Page Info sheet

- ❑ Strengths
- ❑ What doesn't work
- ❑ What does work
- ❑ What your child loves
- ❑ Area's your child is working on
- ❑ The goals or expectations you have for your child

**NAME**  
**AGE**  
**GRADE**

*Teach me to soar and I will*  
Aaliyah Thompson

**VISION STATEMENT**

We envision our daughter living a life of choice. We envision her having relationships she feels are valuable. In her future we envision her doing work that she enjoys and that makes her feel productive. We envision our daughter living a happy and meaningful life surrounded by love and support.

**STRENGTHS**

- Visual learner
- LOVES to read
- Knows ABC's
- Can count to 20
- Social and Kind
- Funny
- Smart
- Happy
- Loves to Dance
- Loves her Friends
- Fast Learner

**WHAT DOESN'T WORK**

- Being Rushed
- Sudden Change in Activity
- Negative Talk
- Yelling
- Assuming I Don't Understand

**WHAT WORKS FOR ME**

- Patience
- Schedule and Routines
- Praise for my Achievements
- Include me
- Believe in my Abilities
- Positive Reinforcement
- Warn me about Transitions

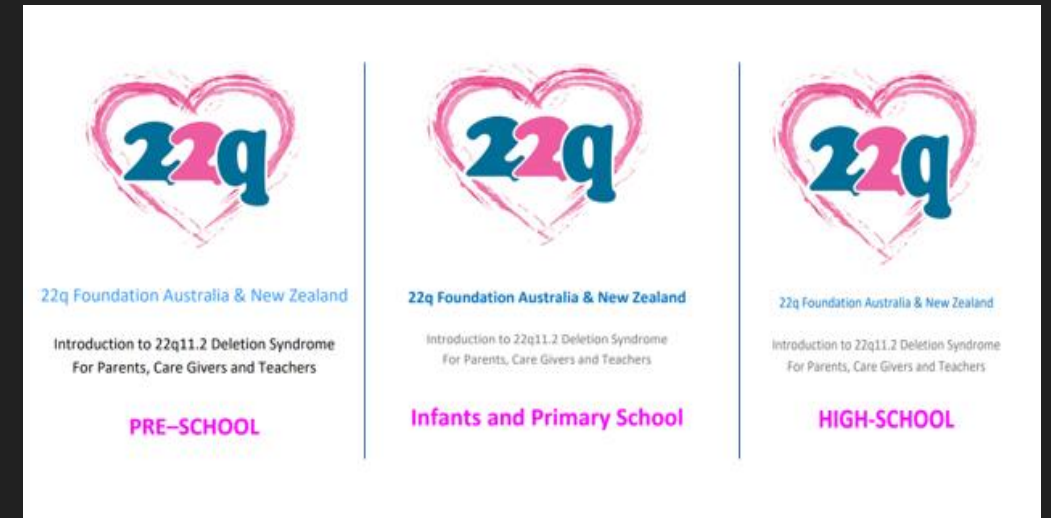
**WHAT I'M WORKING ON**

- Talking in Semences
- Fine Motor Skills, like Writing, Cutting Paper and Coloring!
- Gross Motor Skills, like Running!
- Conversational Speech

**I LOVE:** My Parents, My Brothers, Will & Luke, Mickey Mouse, Tim Bell and Rap Music

# Useful things for teachers

- The introduction to 22q for Teachers and Care Givers <https://www.22q.org.au/school-education>
- Highlight things specific to your child
- Understanding IQ and the different areas of strengths and weakness (Dr Linda Campbell)
  - Work with your school and your psychologist on developing plans for the main areas of concern
  - Understand that sometimes their strengths mask weakness



# IEP- individual education plan

- An IEP is a written plan that will describe the program(s) and special services the student requires to be successful at school. The IEP is developed collaboratively by school staff, parents, therapists and medical staff if appropriate. An IEP can focus on social, academic and independence needs (daily living). IEP meetings are usually held once term to ensure the IEP goals are being met and if not change the goals to assist in confidence and success.
- Meet with all the teachers in one room if possible each term/semester – so everyone is on the same page

Learning Target 1			
Area:	Gross Motor Skills	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 negotiate obstacles in my environment with increased confidence		- Complete a simple obstacle course with 100% accuracy on 3 separate occasions	

Learning Target 2			
Area:	Literacy/ GMS	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 ...	
- Develop the skills necessary for writing		- Adopt the correct posture when writing on 3 out of 4 consecutive days	

Learning Target 3			
Area:	Fine Motor Skills	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 ...	
- Improve my cutting skills		- Cut at least 5 out of 6 shape pictures (circle, square, rectangle, triangle, oval, heart) out accurately on two occasions	



# In the classroom

- Ability to have time out – things can be overwhelming
- Seated at the front of the classroom
- A buddy system
- Visual plans
- Colour coded books
- Extra time to complete tasks
- Homework that is realistic
- Modified work
  - Information broken down into segments – lots of visuals
- Recognising the cues that my child doesn't understand
  - Eg; Day dreaming, fidgeting, disruptive behaviour and sometimes extremely quiet



# Opportunities for success

- ❖ Giving them tasks they are capable of completing will build confidence and self esteem and ultimately success
- ❖ Push to be the best they can be

## Growing Your Kid's SELF ESTEEM

What's the **BIG DEAL** anyways?

Kids with high, positive self-esteem usually...

- Feel happy
- Believe in themselves
- Feel ready to take on challenges
- Have healthy friendships
- Feel strong in their values and choices
- Are willing to try new activities

This can help set up kids for

**SUCCESS**

with good strategies & prepare them for stressful times

### What can I do as a parent?

Help build **acceptance**

- Show your child love and affection
- Listen to your child's interests and opinions to show you care

Help build **confidence**

- Talk about your child's goals and how to reach them
- As your child grows older, give greater responsibility to help build trust
- Work through challenges together to help your child feel capable to overcome obstacles alone in the future

Help build **pride**

- Talk about your child's accomplishments
- Celebrate your child's successes together
- Talk about how to feel proud of yourself even when things may not have turned out as expected

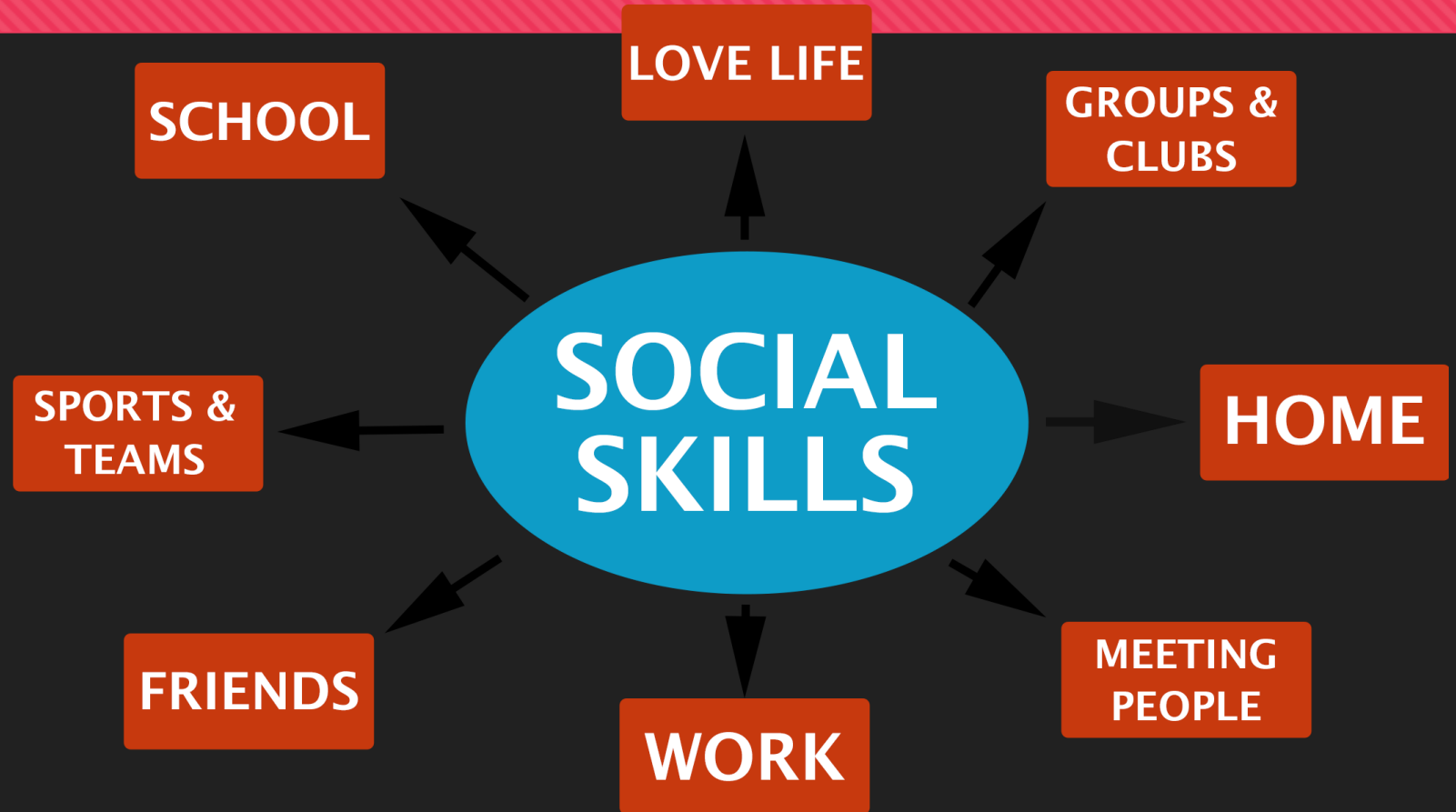
**Heads up**

Constantly praising your child or telling them they are perfect regardless of their actions is not the way to build their self-esteem. Use praise in a genuine way. When your child is experiencing challenges, talk about how it is **ok** and **normal** to fail. This can help to build confidence and resilience.

# Social Skills

SOCIAL SKILLS AFFECT NEARLY EVERY ASPECT OF YOUR LIFE

- Academics is not as important as social interaction
- Give tasks that help them build confidence





# Introducing other students to 22q in the early years – via story telling



## Growing up with 22q11.2 Deletion Syndrome!



HELLO FRIEND!

Have you ever noticed how people are so different from one another? Do you ever wonder why?

Some people are tall, while others are short.  
Some people have blue eyes, while others are brown or green.  
Some people like to read, while others like maths or science.



Some people have lots of friends, while others have two or three close friends.

There are some people who hardly ever get sick and then there are people like me who have 22q.



22q stands for a long medical word called:

### **22q11.2 Deletion Syndrome!**

**But we just call it 22q**

Some people also call it :

**Velo Cardio Facial Syndrome (VCFS) or  
Di George Syndrome or Sequence**



Having 22q means that we may go to the doctor or hospital more often than most kids.

Some of us have special doctors that take care of our hearts.

Some of us have had surgery, sometimes lots of surgeries.

We have scars from all the operations. People often ask us about them.



Some of us get sick more often than other kids.

Some of us talk a little differently and we have to see speech therapists to help us.

Some of us cannot hear very well and we have to wear hearing aids.





We like going to school and learning, but sometimes it takes longer for us to learn than other kids.

That can be really frustrating!



We are really just like any other kid and we like to do lots of fun stuff as well.

We like to dance, go canoeing, play sport and be just like everyone else.



When we first found out about 22q, we were not sure what to think!

Sometimes we were angry because we felt different.

We would ask things like:

Why do I have to go to the doctor all the time?

Why do I need extra help?

Why aren't I like everyone else?

But most of the time we did not really think about it.



We know our families and friends will always be there for us when we need them.

They are always there when we have questions about 22q and how it will affect us.

If you want to know more about 22q ask your parents or doctor or go online to [www.vcfs22q.org.au](http://www.vcfs22q.org.au)

# In the playground

(source: Prepared by Mr Neil Nicoll, Psychologist (Psychologist No PS0003047), CHERI

- Classrooms are generally quite structured, ordered, calm and predictable. Rules and expectations are clear, tasks and activities are well defined, and the transition from one activity or lesson to the next is structured. This is the opposite of most playgrounds in schools
- Use peer support systems and buddy systems to give children additional support and supervision
- Model, rehearse and reinforce appropriate play skills
- Teach the child more appropriate social interaction and play skills.



- Teach the child specific problem-solving strategies when it is still too hard. For example, the child can go to the library or work on a computer or read.
- Incorporate obsessions and intense interests into play sequences, for example 'music club'. or make these into useful activities, for example categorising books in the library

# Remember - They Can Achieve



# Slowly, Slowly Catchy Monkey

- It won't be an overnight success – 'slowly-slowly catchy-monkey'
- Offer different opportunities for learning
- Different environments
- Refresh + improve



Thank you!! [www.22q.org.au](http://www.22q.org.au)

