

# Anxiety in Williams Syndrome

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# Contents

- Who are we?
- What is anxiety and what do we know about anxiety in WS?
- How to spot signs of anxiety
- Strategies
- Where to find further information

# Who are we?



# Williams Syndrome Research at the CCND

Currently undertaking three year research project:

Anxiety in adolescents and adults - 12+

1. Interview study ( $n=13$ ,  $M\ age=21.92$ ,  $SD=11.12$ ) ✓
2. Online international survey study (*current*  $n=19$ )  
*Comparison groups: FXS (current*  $n=27$ *), PWS (current*  $n=7$ *)*
3. Direct assessment study (UK) – January 2017



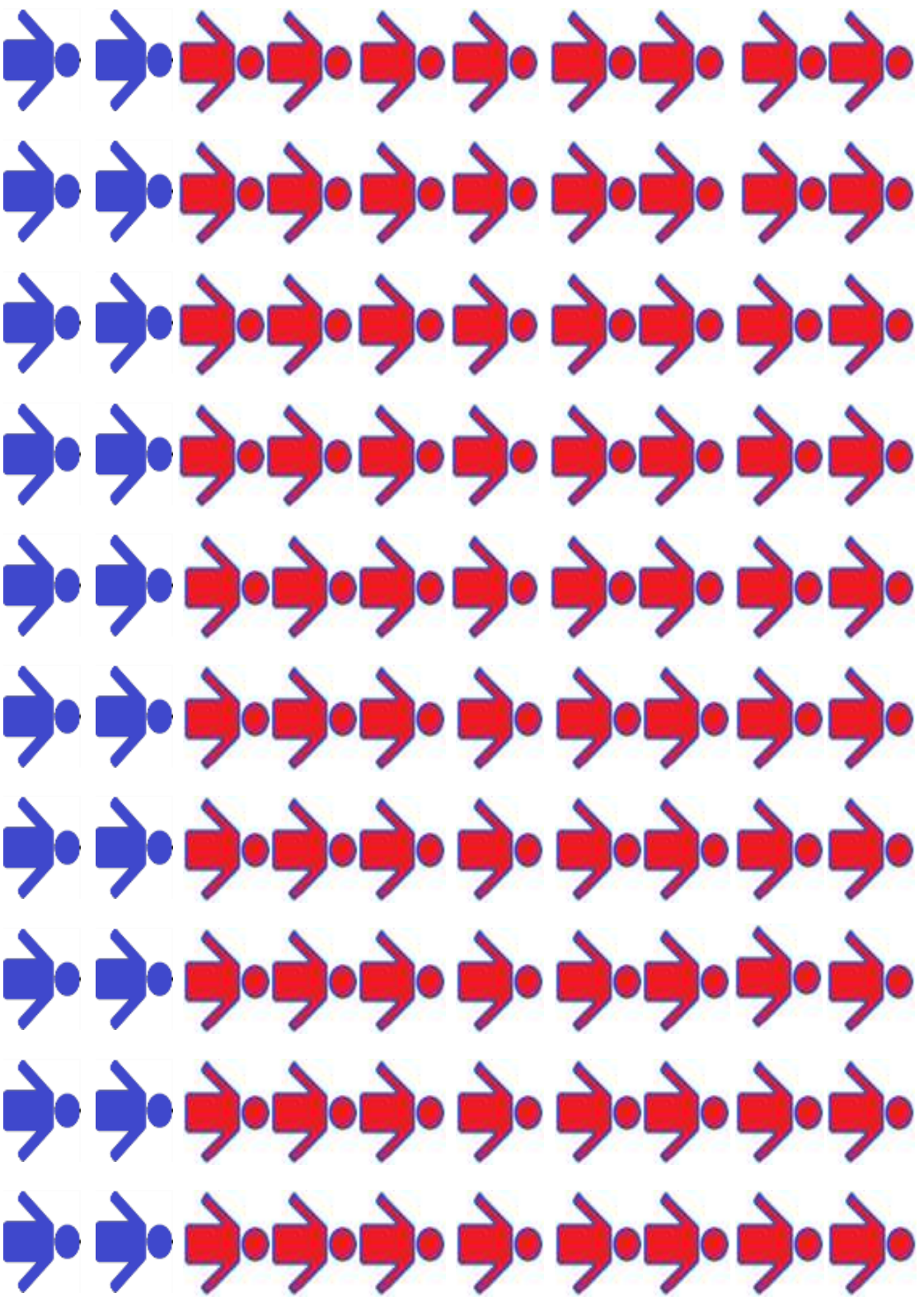
# What is anxiety or worry?

“a feeling of worry, nervousness, or unease about something”

- **When is it ‘normal’?**
  - Situation that is threatening/difficult
  - Example: public speaking
  - Anxiety stops during or after the event
- **When is it a problem?**
  - Constant anxiety all the time
  - No reason
  - Out of proportion to threat of situation



Rare genetic syndromes  
(e.g. Williams, fragile-X  
or Cornelia de Lange  
syndromes





# Williams Syndrome: Anxiety Prevalence

*Royston et al., 2016*



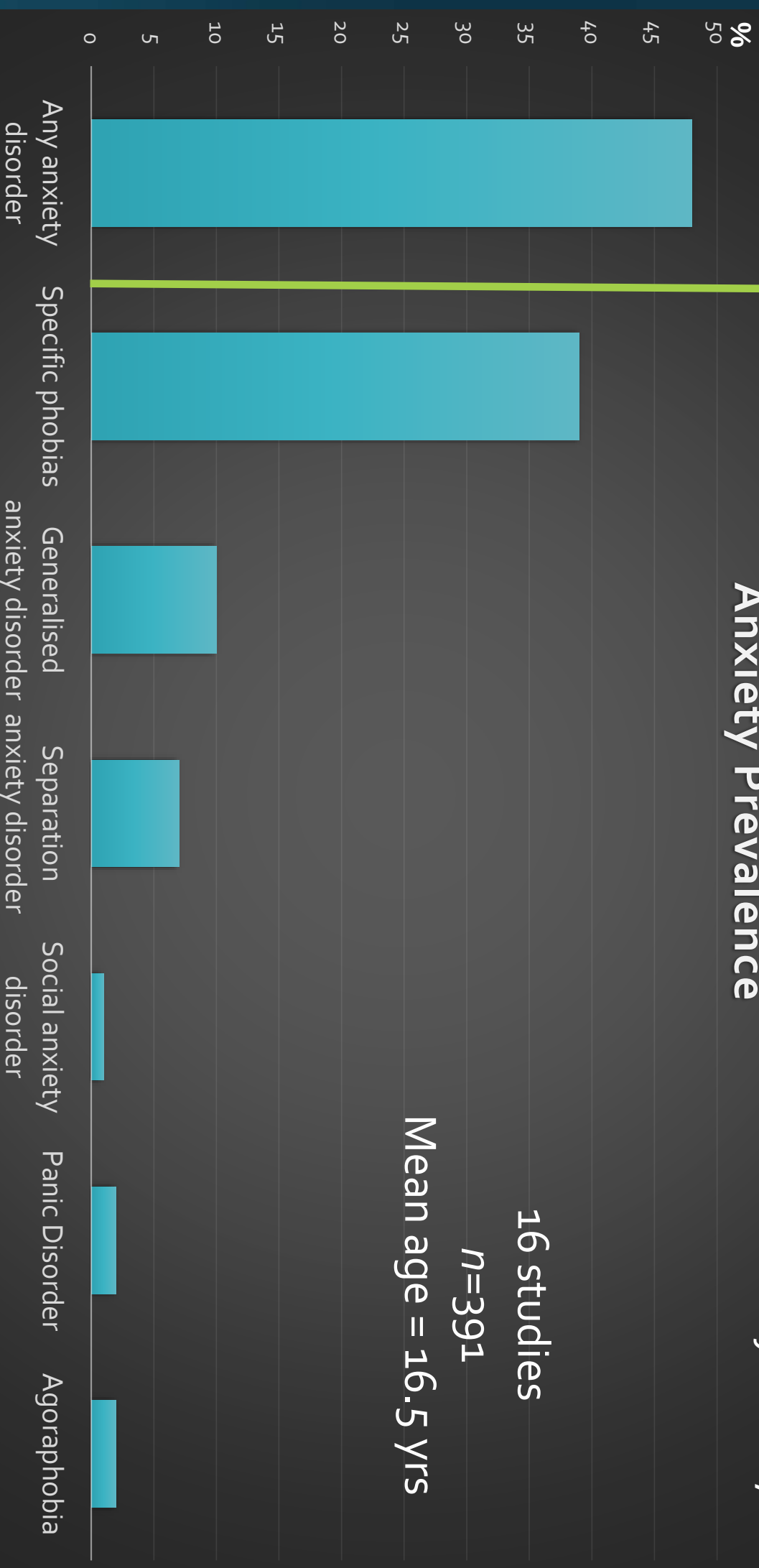
16 studies

$n=391$

Mean age = 16.5 yrs

*Royston et al., 2016*

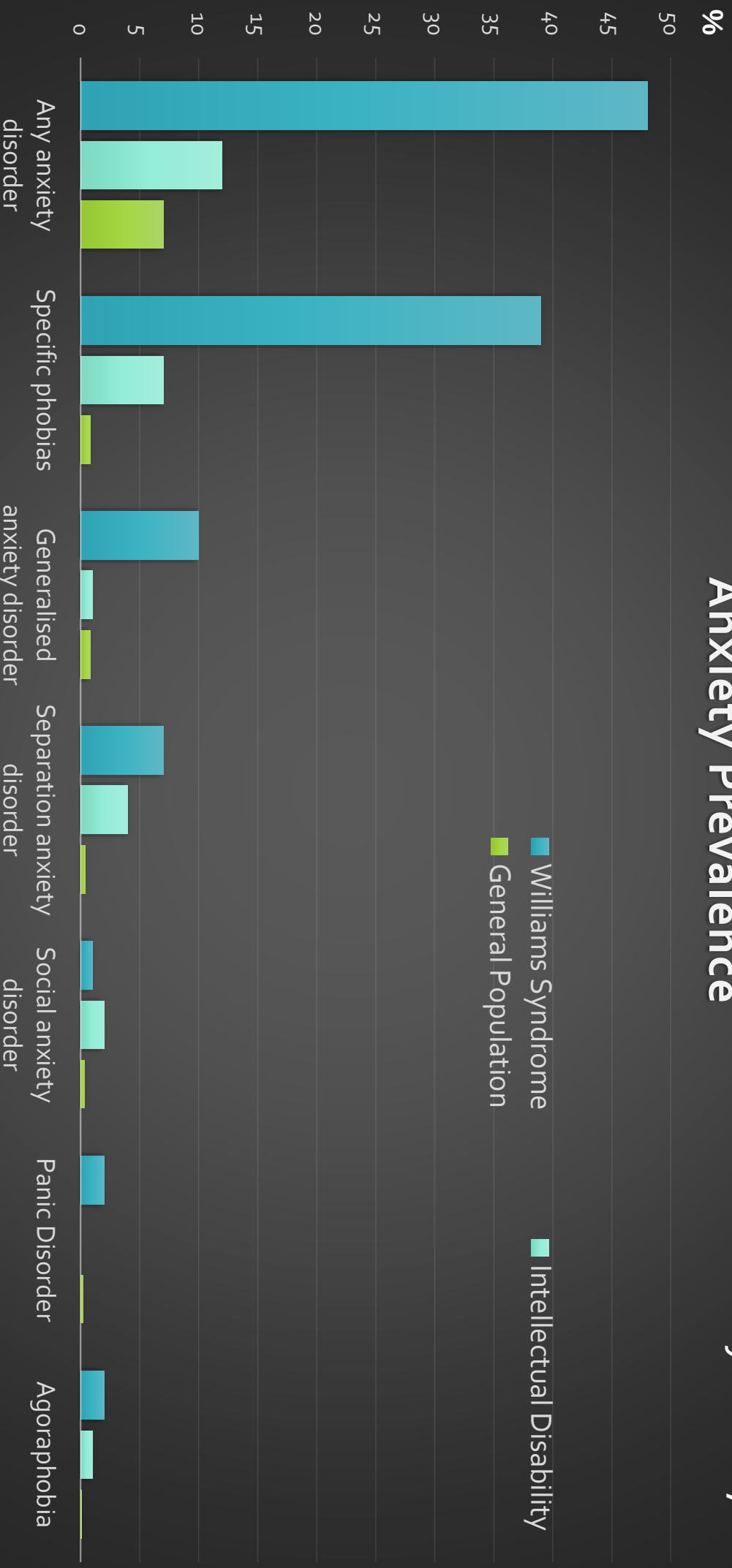
## Anxiety Prevalence



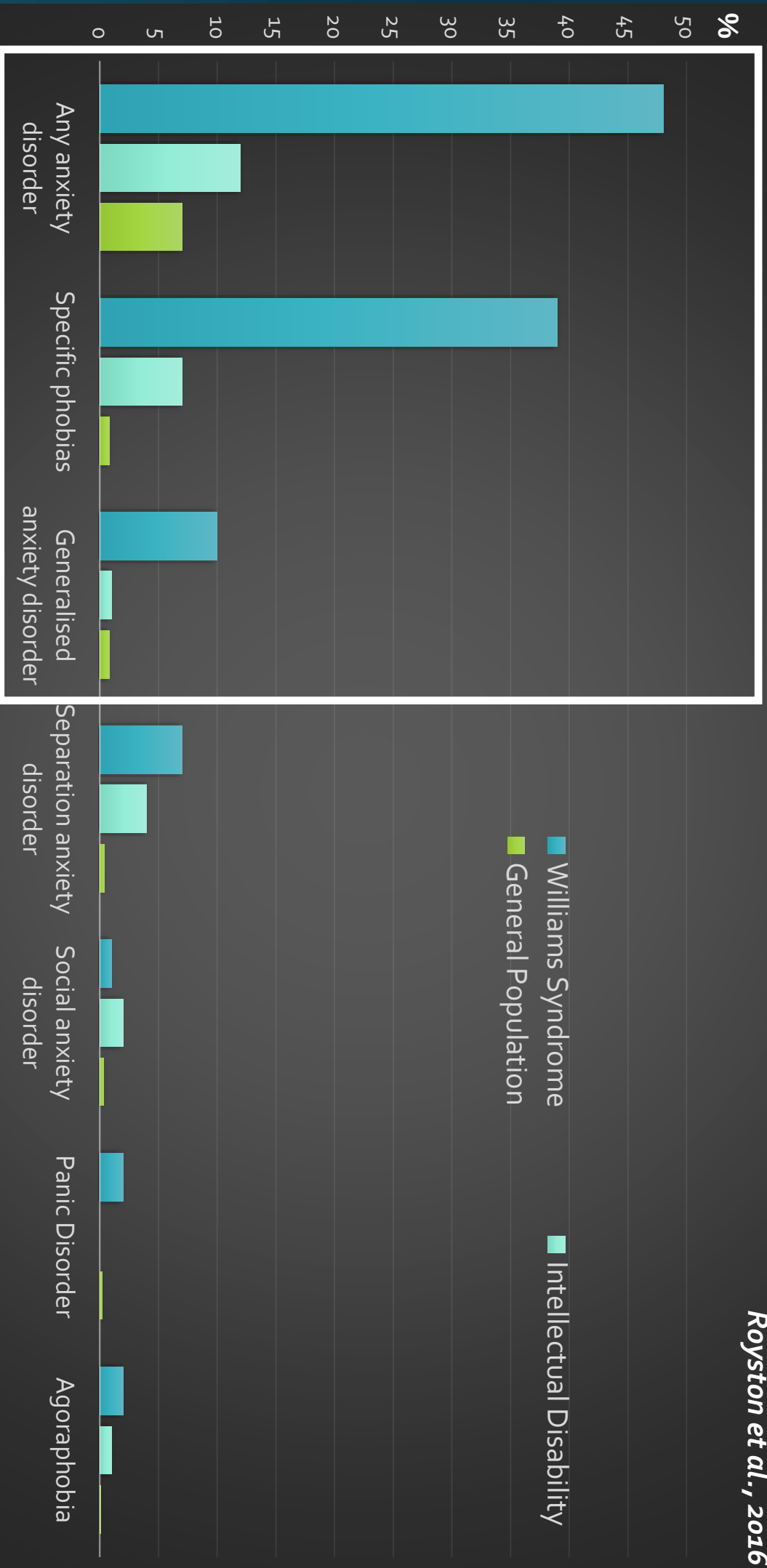


# Anxiety Prevalence

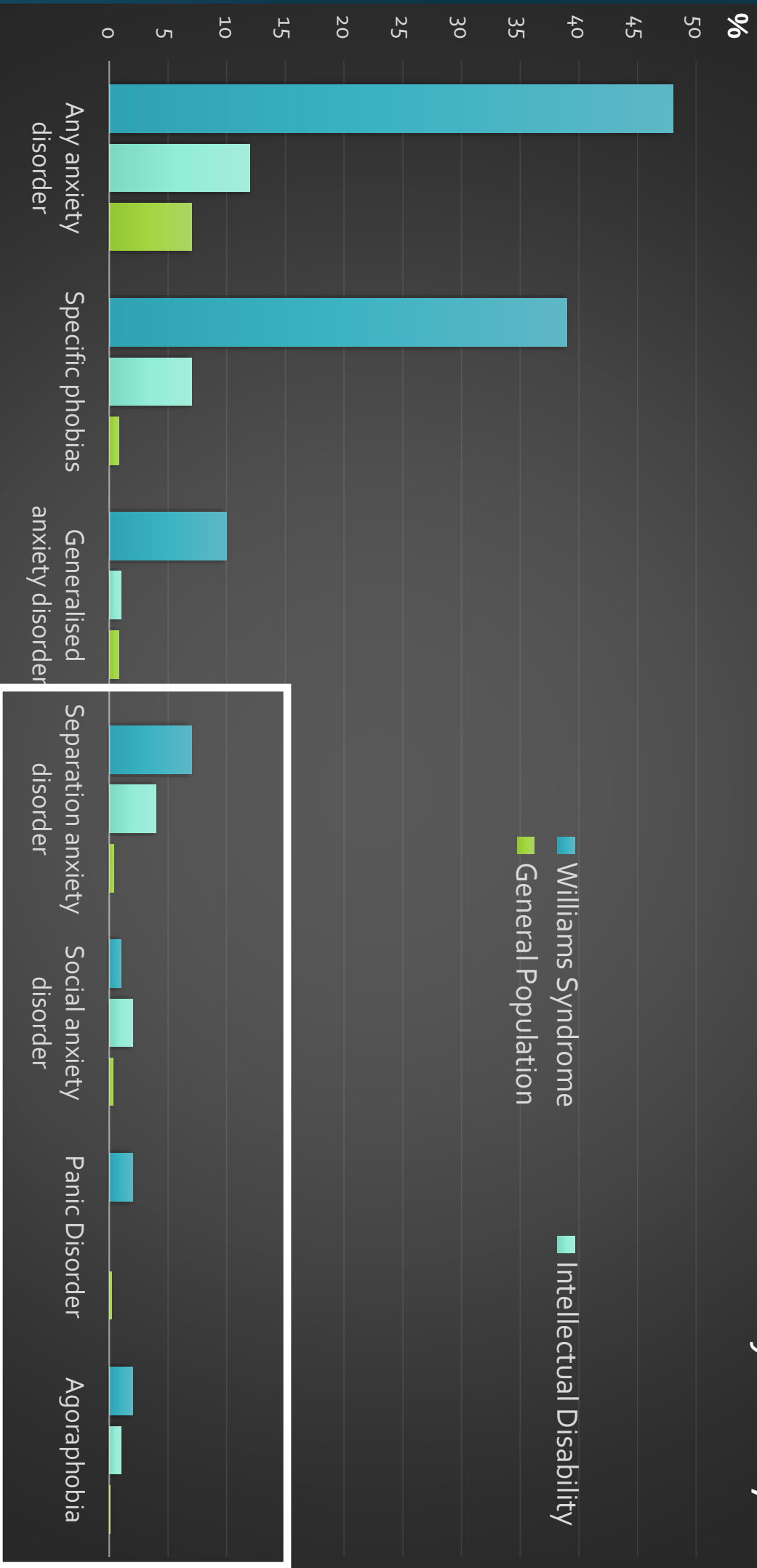
*Royston et al., 2016*



*Royston et al., 2016*



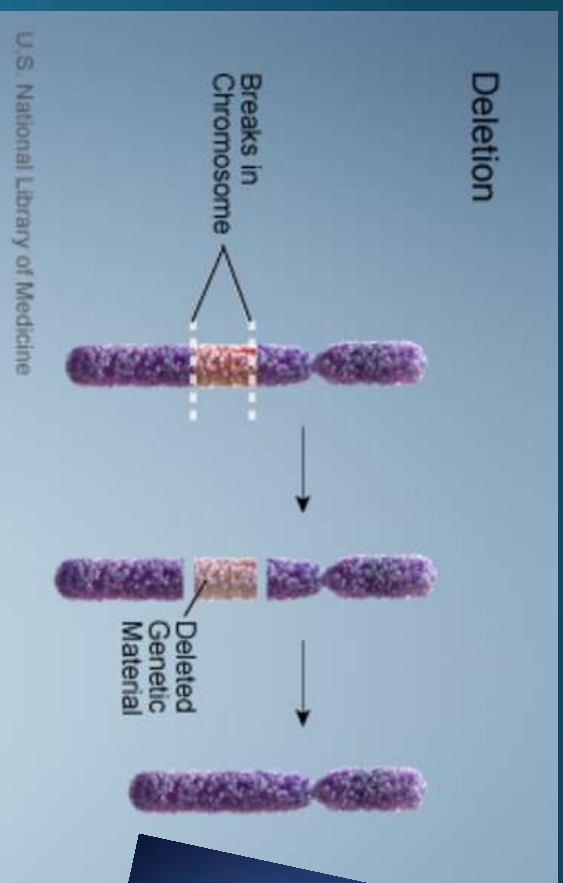
*Royston et al., 2016*



# Anxiety in MS

Not related to number of stressful life events or level of ability

Social difficulties, hypersensitivity to sound, executive functioning



# Specific phobias

Irrational fear relating to an object, situation or event

Risk in WS: x5.6

Noise



Hospitals/Doctors/Injections



Storms



Animals



Unpredictability?



# Other common anxiety triggers

- New situations
- Unpredictability
- Routine changes
- Anticipation of future events
- Performance situations/increased demands
- Other people being upset
- Social situations

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# Other common anxiety triggers

- New situations
- Unpredictability
- Routine changes
- Anticipation of
- Performance situations,
- Other people being upset
- Social situations



But, people report low levels of social anxiety in Williams Syndrome?

# Other common anxiety triggers

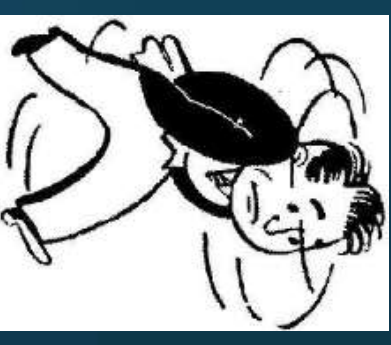
- New situations
- Unpredictability
- Routine changes
- Performance situations/increased demands
- Other people being upset
- Anticipation of future events
- Social situations



INTOLERANCE OF  
UNCERTAINTY?

# Generalised Anxiety Disorder

- Excessive and uncontrollable worry, not linked to a specific event
- GAD linked to Intolerance of Uncertainty in general population
- Risk in WS x10
- GAD increases with age (Dodd & Porter, 2009; Leyfer et al., 2006)



# Change over time?

*Woodruff-Borden et al. (2010):*

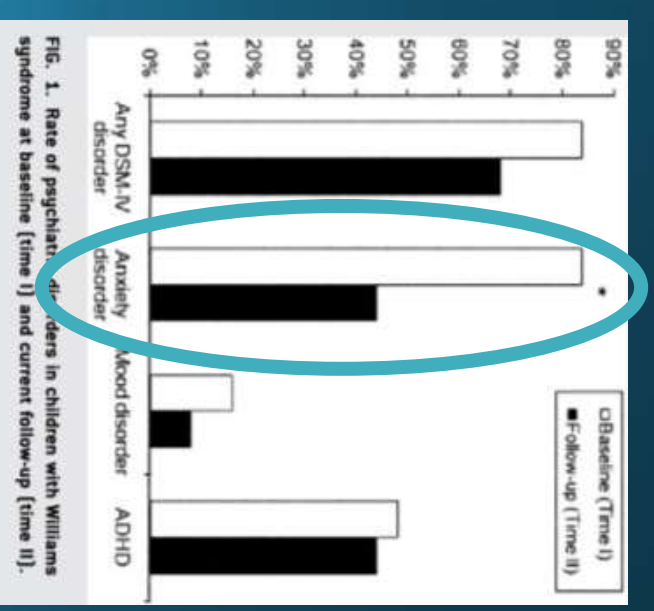
N=45 (mean age T<sub>1</sub>=6.7 yrs; mean age T<sub>2</sub> = 10.8 yrs)

- 5 year follow up
- 62.2% showed anxiety over time
- 72.2% with anxiety developed more anxiety disorders at later assessments

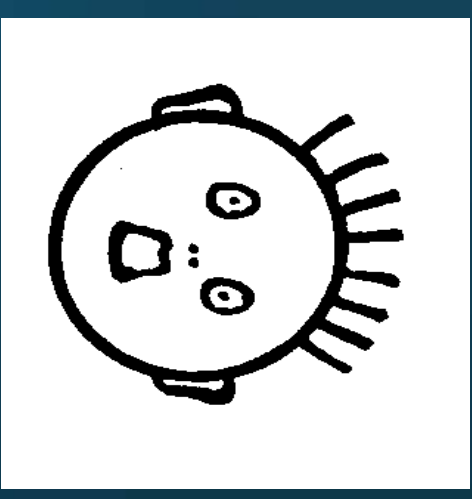
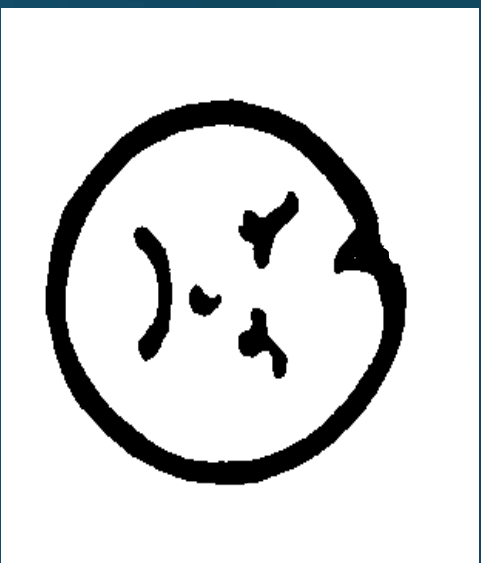
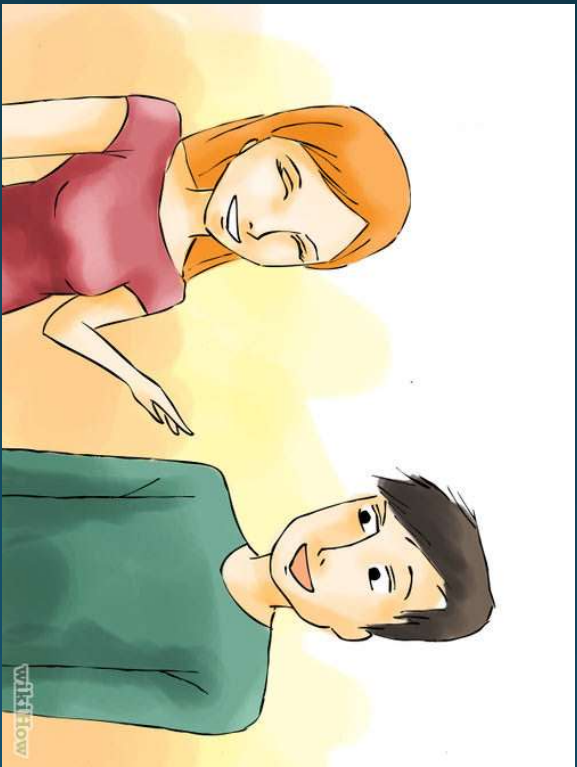
*Green et al. (2011):*

n=25, (mean age = 13.1, SD = 5.2)

- follow up 3-9 years later
- 84% → 44%







# Knowing when someone is worried?



TV show

# What to look for...

<b>Changes to the body:</b> <ul style="list-style-type: none"><li>• fast and irregular heartbeat</li><li>• sweating</li><li>• tiredness</li><li>• muscle tension</li><li>• dizziness</li><li>• trembling</li><li>• pale complexion</li><li>• stomach aches</li><li>• nausea</li></ul> 	<b>Changes to thoughts/ thinking patterns:</b> <ul style="list-style-type: none"><li>• inability to concentrate</li><li>• repetitive thoughts about perceived threat</li><li>• concerns about losing control</li><li>• inability to relax</li></ul> 	<b>Changes to emotions</b> <ul style="list-style-type: none"><li>• irritability</li><li>• feeling worried</li><li>• distress</li><li>• crying</li></ul> 	<b>Changes to behaviour</b> <ul style="list-style-type: none"><li>• avoiding situations</li><li>• fidgeting/ moving more than usual</li><li>• seeking proximity</li><li>• more repetitive behaviours</li></ul> 
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Many signs of anxiety overlap with signs of physical health difficulties.



# The vicious cycle of anxiety

**Situation**  
e.g. parent walks their child to the park where there might be dogs

**Anxiety**  
Child's heart rate increases, they feel tense and worried

**Child is vigilant for danger**  
The child's attention becomes focused looking for dogs as they approach the park

**Long term: anxiety increases.**  
Loss of confidence of coping. Child more likely to use behaviours to avoid dogs in the future. Parent is more likely to avoid the park in future

**Child experiences short term relief**

**Child engages in behaviour to escape any dogs**  
Refuses to go into the park. Pulls parents arm to move away from any dogs that come near



# Understanding the triggers for anxiety

Knowledge of the type of anxiety and triggers associated are important

Date/Time	What happened before? Immediate Trigger	How long did it last?	What did the person worry about?	What happened afterwards? How did the person calm down?

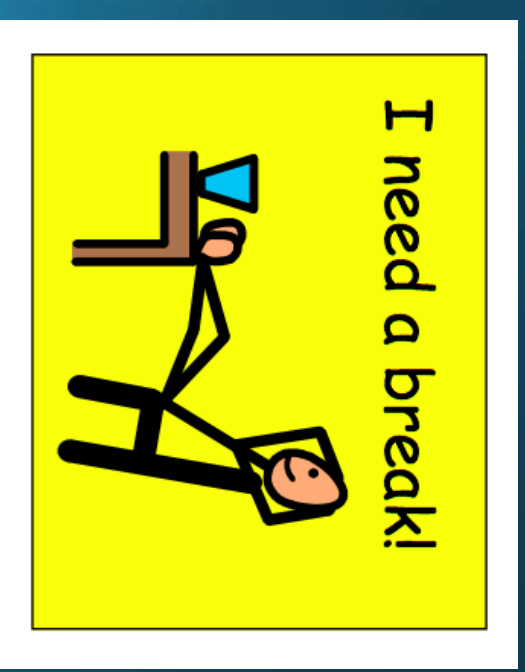
# Overview: Strategies

## Interventions

- Practice labelling emotions and increasing communication
- Increase coping
- Make life more predictable
- Addressing sensory issues
- Not all strategies work for everyone

# Labelling emotions and increasing communication

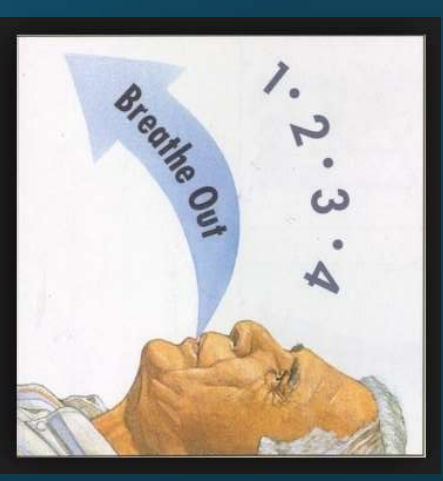
- Knowing you have a way to let people know that something is difficult can reduce anxiety
- Card or picture cue to 'take a break' or 'leave the situation'
- Avoidance = more likely to experience anxiety in the future: pair this strategy with gradually increasing the amount of time the person spends in feared situation
- Having an allocated "worry time"



# Increasing the person's coping skills

## Self-calming strategies

- Listening to calming sounds or music  
(Blomberg et al., 2006; Dykens et al., 2005)
  - Deep breathing
  - Squeezing a ball
- Strategies should be used to help reduce anxiety in difficult situations rather than avoiding the situation



# Making life more predictable

- **Endure predictable pattern to the day**
  - Visual schedules
  - Use social stories
  - Increase choice
- Once the person has a predictable routine it may be possible to gradually introduce more flexibility so that the person can begin to tolerate a more variety.
  - **Slowly!** Monitor progress.
- **Use a cue to indicate a change is coming**
  - Not too early as this anticipation can increase anxiety



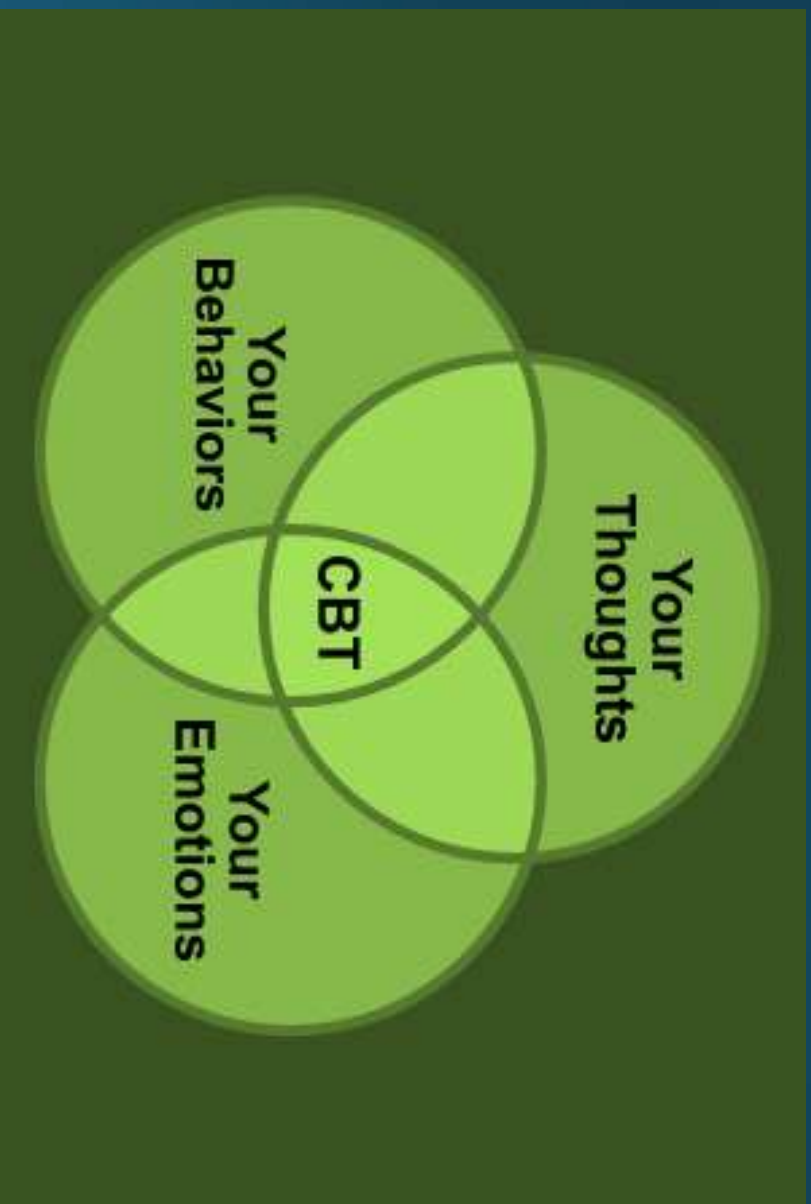
# Addressing sensory issues

Example: hypersensitivity to noise,  
ear pain

- Treat physical health problem (i.e. an ear infection)
- Strategies: ear defenders for loud noises



# Cognitive behavioural therapy vs. Behavioural approaches





# In summary

- Higher levels of anxiety are associated with WS
- Anxiety can arise for various reasons
- People with WS may have fewer strategies available to cope with this unpredictability
- There are several things that we can do to try to reduce anxiety
- There is still a lot for us to learn!

# Further information

Cerebra guide for parents



Search for 'cerebra anxiety guide'

Dr Debbie Ribby, Durham UK

<p><b>Anxiety in children with Williams Syndrome</b></p> <p><i>A Guide for Primary School Teachers</i></p> 	<p><b>Anxiety in young people with Williams Syndrome</b></p> <p><i>A Guide for Secondary Education</i></p> 
<p>Durham University williams syndrome Newcastle University</p> <p><small>Show previous page   Next Arrow</small></p>	<p>Durham University williams SYNDROME FOUNDATION Newcastle University</p>

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# Thank you for listening



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