



CENTRE FOR AUTISM
MIDDLETOWN

EMPOWERING PARENTS: Using parental training to reduce anxiety for children and young people with Autism.

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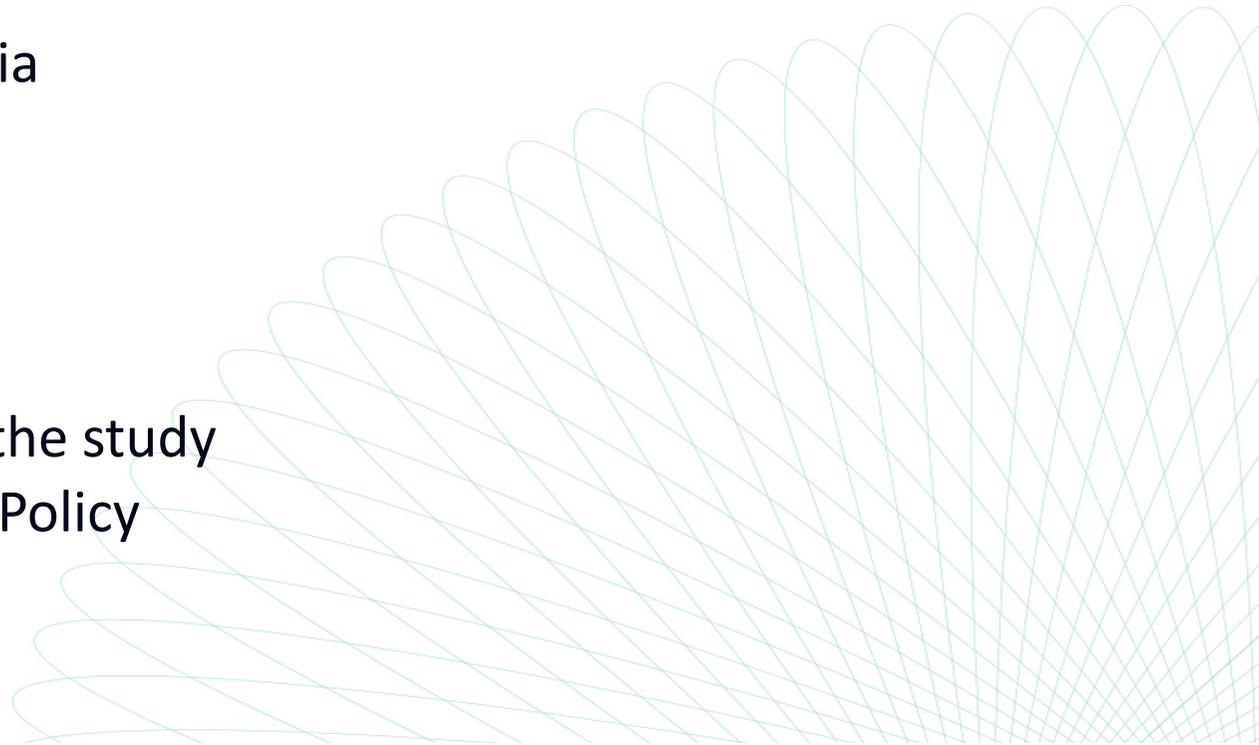
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Overview of presentation

1. Background on why we conducted the parental training study
2. Objectives of the study
3. Methodology
4. Inclusion and exclusion criteria
5. Procedure
6. Outcome measures
7. Findings
8. Limitations
9. Summary and Conclusion of the study
10. Implications for Practice and Policy



Why conduct parental training research?

- **Anxiety is a common co-occurring condition across autism (Rodgers et al., 2012)**
 - **Prevalent in around 40% of CYP with autism (van Steensel et al., 2011) compared to 27% of typically developing (TD) CYP (Costello et al., 2005)**
 - **CYP with autism have higher anxiety levels compared to TD CYP, this difference increases with IQ. (van Steensel & Heeman, 2017)**
- **Demand for anxiety support outweighs specialist provision in the UK, including Northern Ireland (NAS, 2010)**

Objectives



To determine the...

- efficacy of parental training, as a method of support in reducing the anxiety experienced by CYP with autism.
- impact of anxiety management training on parental feelings of efficacy in relation to them managing their CYP's anxiety.

Methodology

- A mixed methods approach
- Ethical approval - Office for Research Ethics Committees Northern Ireland (OREC NI)
- A feasibility pilot Study - Parents of CYP (10 years -18 years) with autism - Northern Ireland and Republic of Ireland



Inclusion Criteria

Parent/caregiver attending sessions should:

- Reside with a CYP with a formal diagnosis of autism
- Have good verbal ability and no cognitive impairment
- Be committed to attending all five anxiety management workshops and participate in pre and post workshop assessments and interviews

The CYP with autism should:

- Have observable anxiety within home or school
- Aged between 10 years and 18 years
- Be in mainstream school



Exclusion Criteria

The CYP with autism should not:

- Have any additional behavioural or mental health difficulties
- Be on any medication for anxiety or difficulties with mood or behaviour
- Be currently receiving any other intervention for anxiety



Procedure



Online registration form

- Inclusion/exclusion criteria applied

Information Sheets & Consent

- Return consent forms

Pre Intervention

- Complete 3 Postal Questionnaires

Training Workshops

- Attend 5 parent training workshops

6 Weeks post intervention

- Complete 3 postal questionnaire
- Participate in a telephone interview

Outcome measures

Demographic profile

- Developed by MCA: Education Level; Current interventions; Previous training

Anxiety Scale for Children – Autism Spectrum Disorder – Parent Version (ASC-ASD-P, 2015)

- 24 Item Questionnaire: Separation Anxiety; Uncertainty; Performance Anxiety; Anxious Arousal

Nisonger Child Behaviour Rating Scale (NCBRF) 1995

- A standardised instrument for assessing child and adolescent behaviour with intellectual and developmental disabilities

Johnston and Mash parent Self-Efficacy Scale 1989

- 16 item Likert-Scale Questionnaire
- Parental Confidence: Satisfaction & Efficacy

Telephone Interview

- 13 Questions: Likes/ dislikes; Impact of training on CYP anxiety

Intervention – 5 Parent Training Workshops

- 1 - **Theory**, research and assessment of anxiety
- 2- **Action** - identifying triggers of anxiety, psycho-educating child on emotions
- 3 - **Sensory Processing**
- 4- **Strategies**
- 5. **De-sensitisation** (Facing your fear.



Intervention - 5 Parent Training Workshops

- A presentation
- Worksheets
- Active participation during session
- Homework
- Reflection on previous weeks homework



Examples

- Learn to identify sensory related behaviours e.g. sensory training
- Manage sensory environment e.g. noise, temperature, lighting
- 'Calm Kit'
- Deep pressure techniques and strategies



Examples

Identify emotions –

5 point scale

5 I am not safe. I need to leave before anyone gets hurt.



4 I am losing control. I need a Chillville break to calm down.



3 I am not fully in control. I need to take deep breaths.



2 Things are ok. I can handle it.



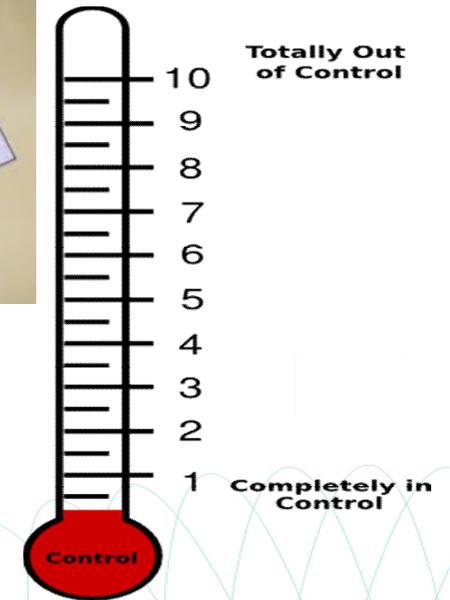
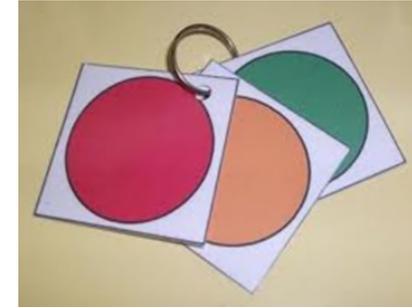
1 I feel super



| | Feels Like | What I can do |
|----------|---|---|
| 5 | I'm going to break down (cry, begin pacing, bang my head). | I can request to leave the room and go to the quiet room. |
| 4 | My stomach is starting to hurt and I'm having difficulty concentrating. | I can ask to talk to an adult. I can listen to my calming music (headphones). |
| 3 | I'm feeling uneasy and I'm starting to sweat. | I can refer to my coping cards and use deep breathing. |
| 2 | I feel ok. I can handle the situation | Self-talk and reassure myself I can do it! |
| 1 | I feel great No Problem | |

Examples

- Individualised system to communicate growing anxiety e.g. traffic lights, volcano, kettle, thermometer
- Access to a quiet space
- Access to special interest
- Negotiate when the child is calm



Examples

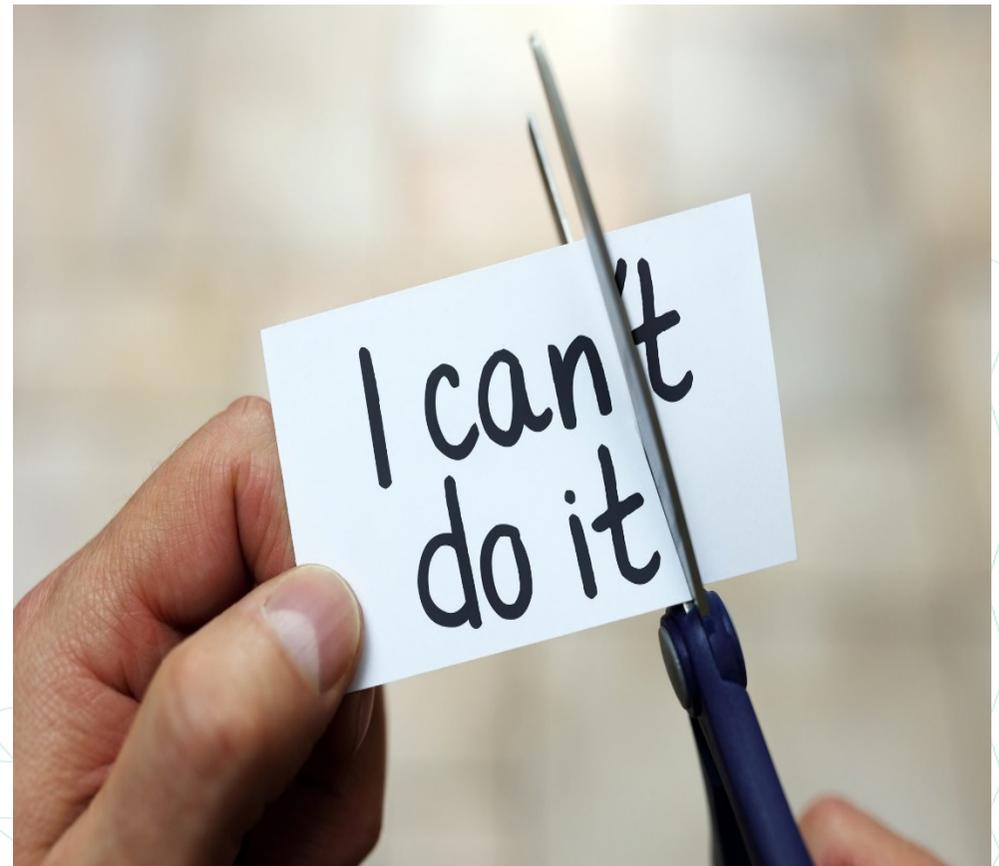
- **Go to your relaxing place (guided imagery)**
- **Look at the picture of your relaxing place**
- **Do your breathing exercises**
- **Feel your body relax**



Face your Fear

How parents could support their child

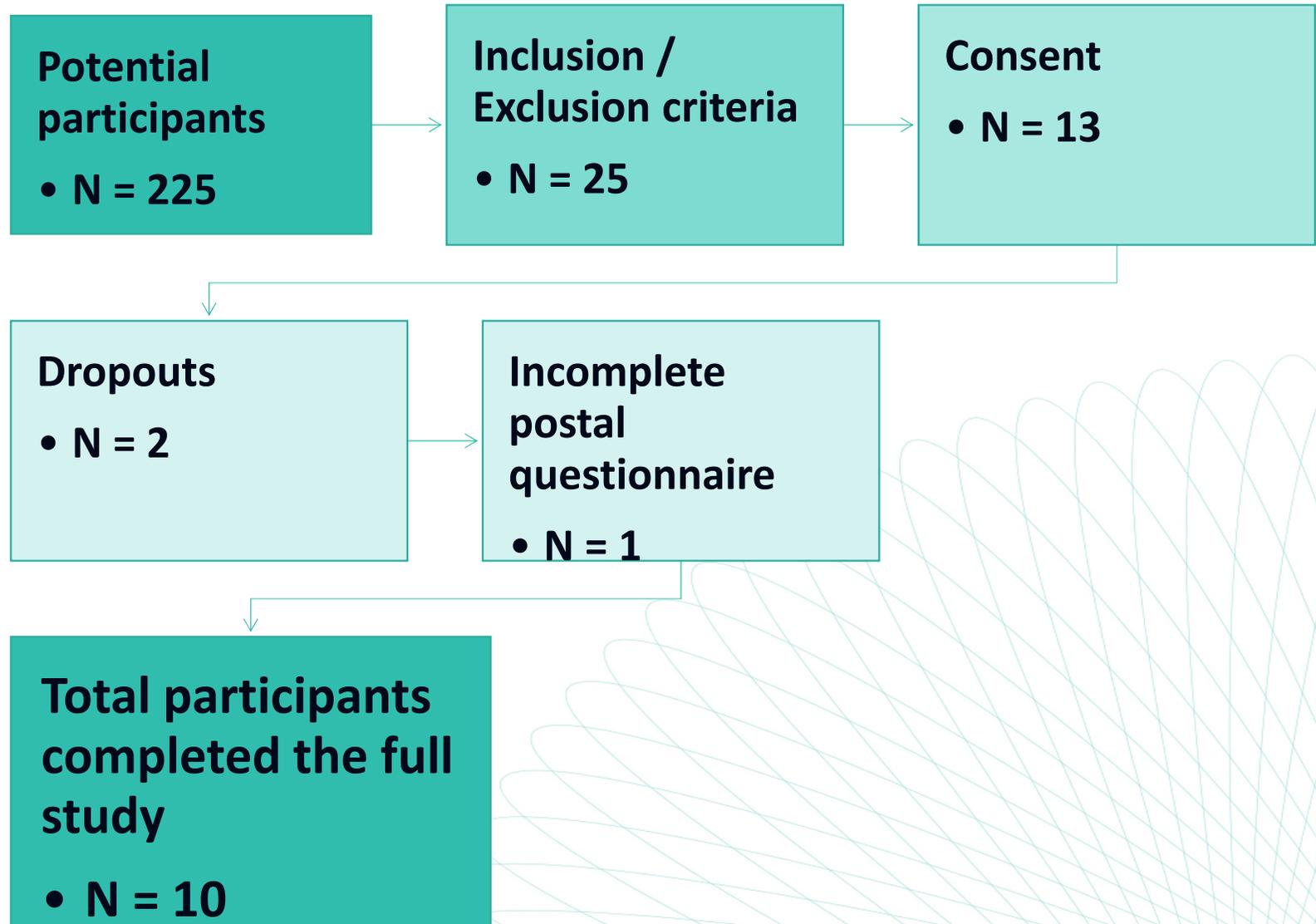
- Record and reflect
- Practice using **individualised strategies** (e.g. breathing)
- Try desensitizing strategies around anxiety trigger / fear
- **Step by step**
- Model appropriate and positive behavior (parents)
- Celebrate all success
- Parents anxiety



Data Analysis

- All data was anonymised
- Descriptive statistics - demographic information and responses to items within each questionnaire
 - The NCBRF (1995) and ASC-ASD –P (2015), total scores and scores within each subscale were categorised as ‘never’, ‘sometimes’, ‘often’ or ‘always’ occurring.
 - The Johnston and Mash Parent Self Efficacy Scale (1989) scores were categorised as either ‘high’, ‘moderate’ or ‘low’.
- Telephone interviews - thematic content analysis.

Results



Demographic Information

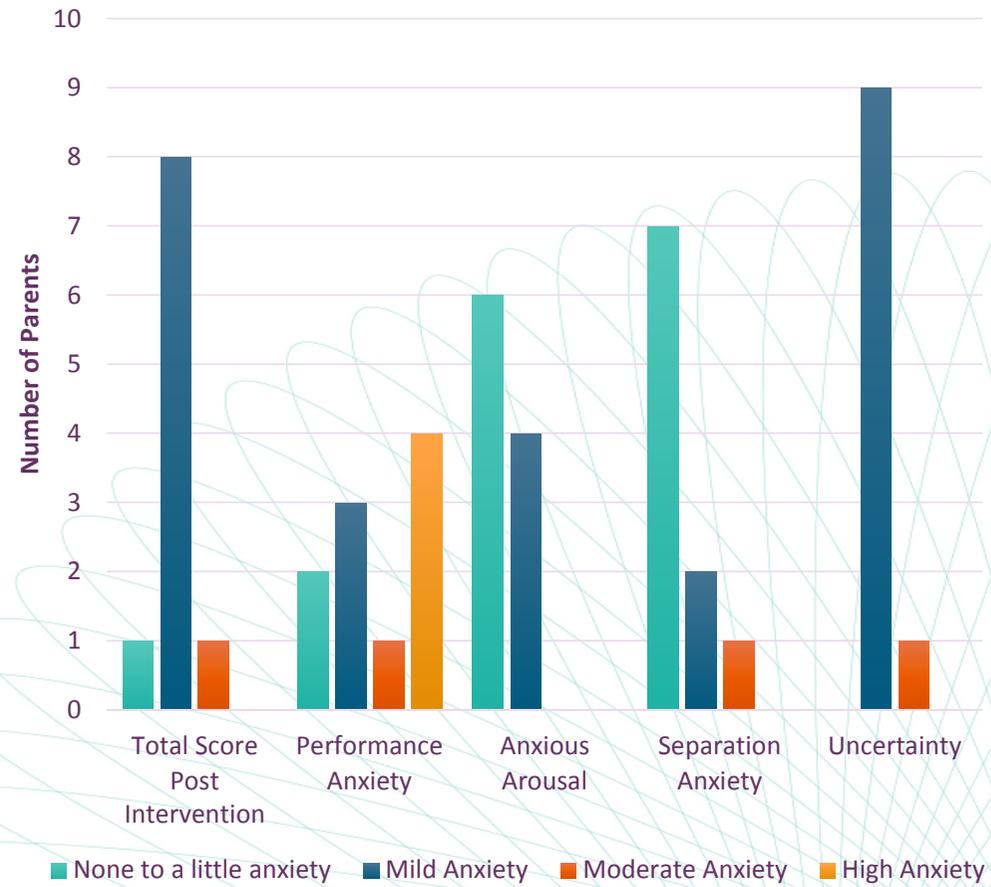
- **All English speaking Mothers (N = 4 NI, N = 6 ROI)**
- **Aged between: 41 – 50 years (90%), 51 – 60 years (10%)**
- **3rd level education (50%) or above (40%)**
- **60% were employed and 40% stay at home mums**
- **90% were married, 10% separated**
- **80% had received no anxiety training or interventions prior to the study**
- **All the participants had sons Aged 10 -14 years**
 - **With a diagnosis of Autism (50%); Asperger's Syndrome (40%); or Autism Spectrum Disorder and Dyspraxia (10%)**

Anxiety Scale for Children – Autism Spectrum Disorder – Parent Version (ASC-ASD-P, 2015).

Anxiety Levels Pre Anxiety Training Workshops

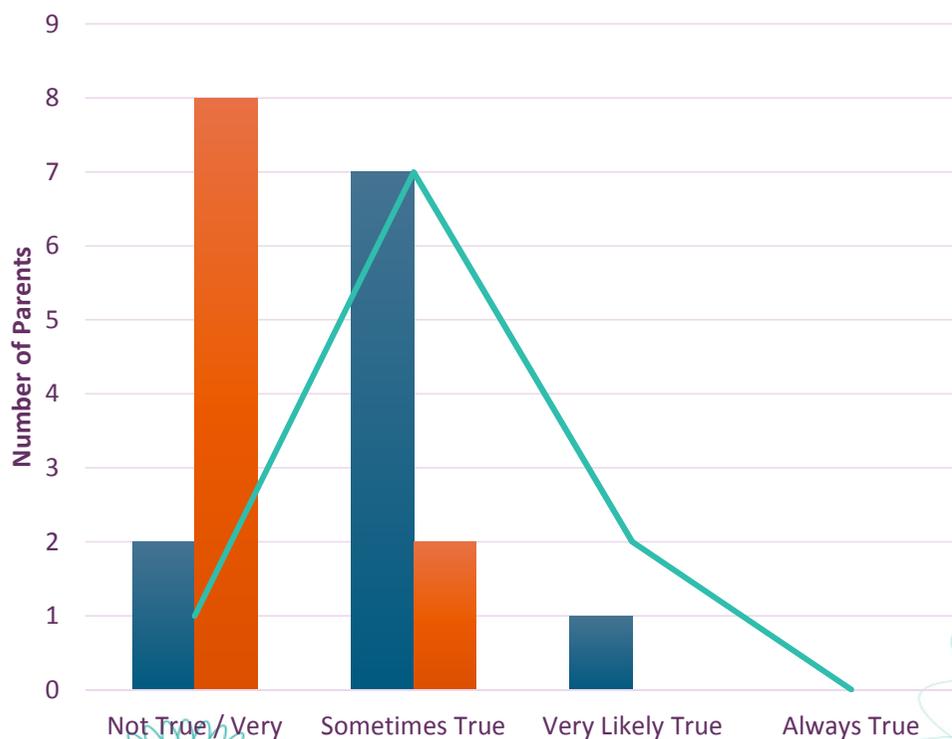


Anxiety Levels Post Anxiety Training Workshops

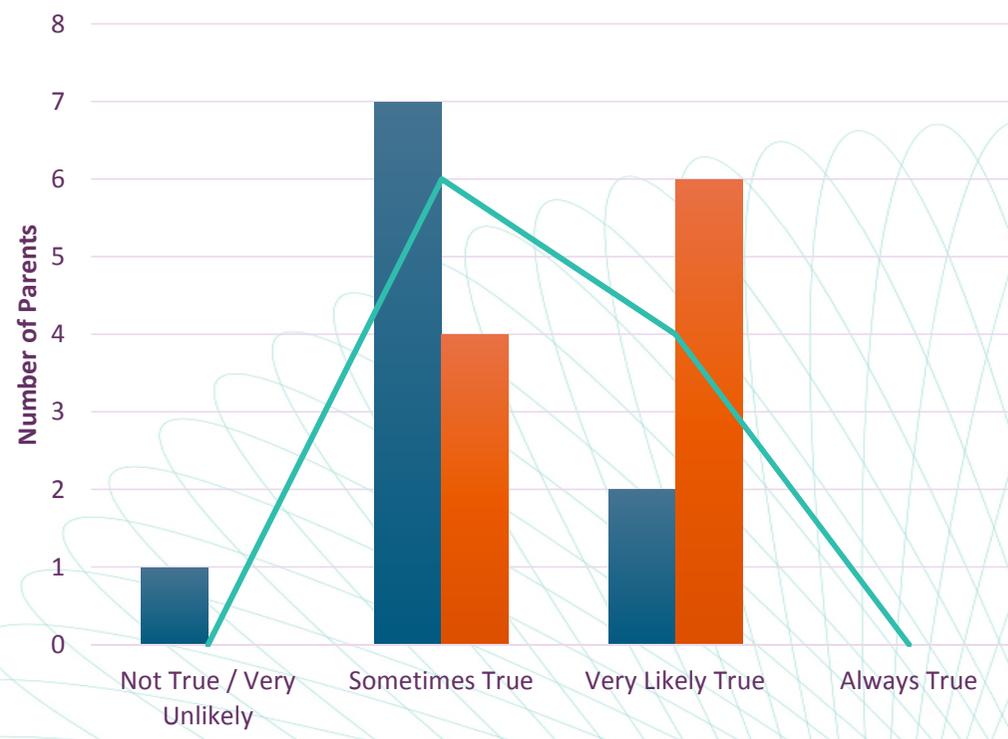


Nisonger Child Behaviour Rating Scale (1995)

Nisonger Positive Behaviours Pre Anxiety Training Workshops

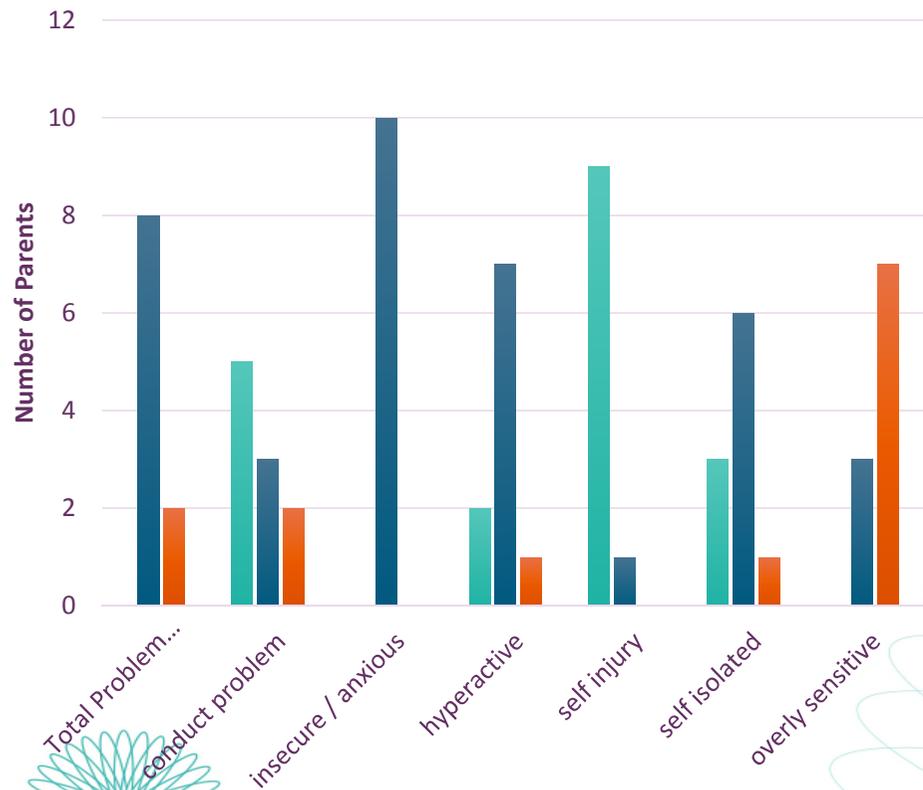


Nisonger Positive Behaviours Post Anxiety Training Workshops

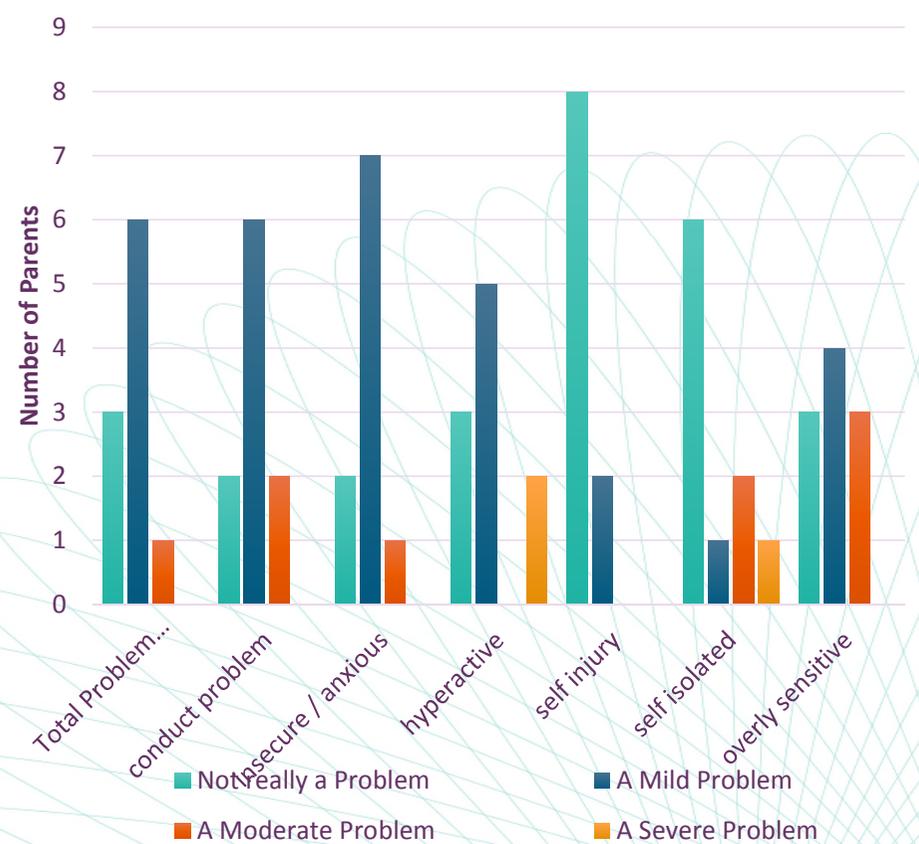


Nisonger Child Behaviour Rating Scale (1995)

Nisonger Problem Behaviours Pre Anxiety Training Workshops

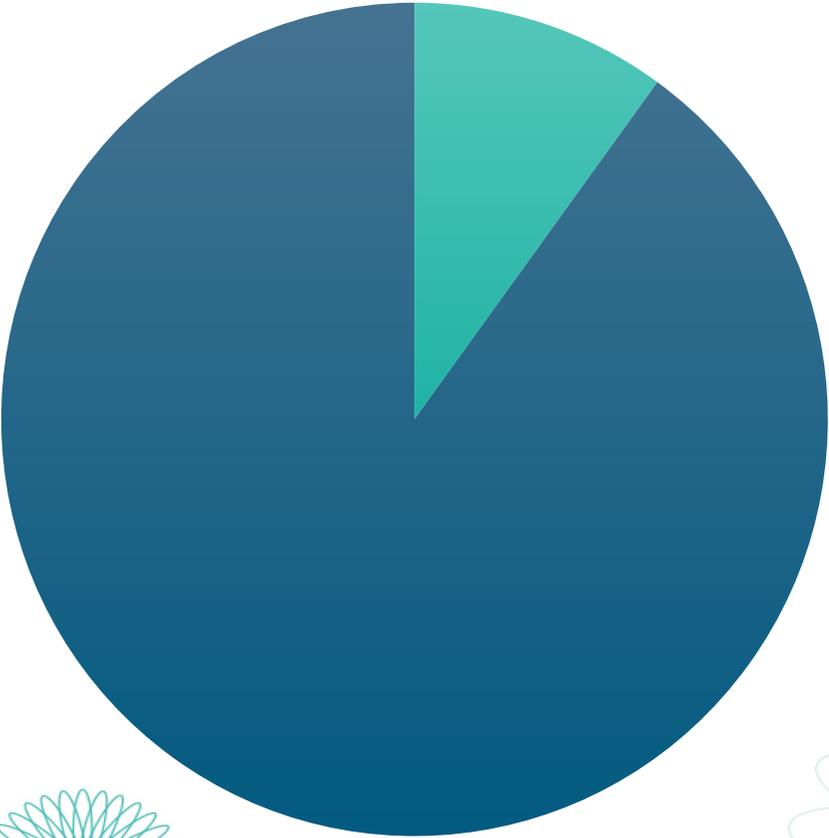


Nisonger Problem Behaviours Post Anxiety Training Workshops

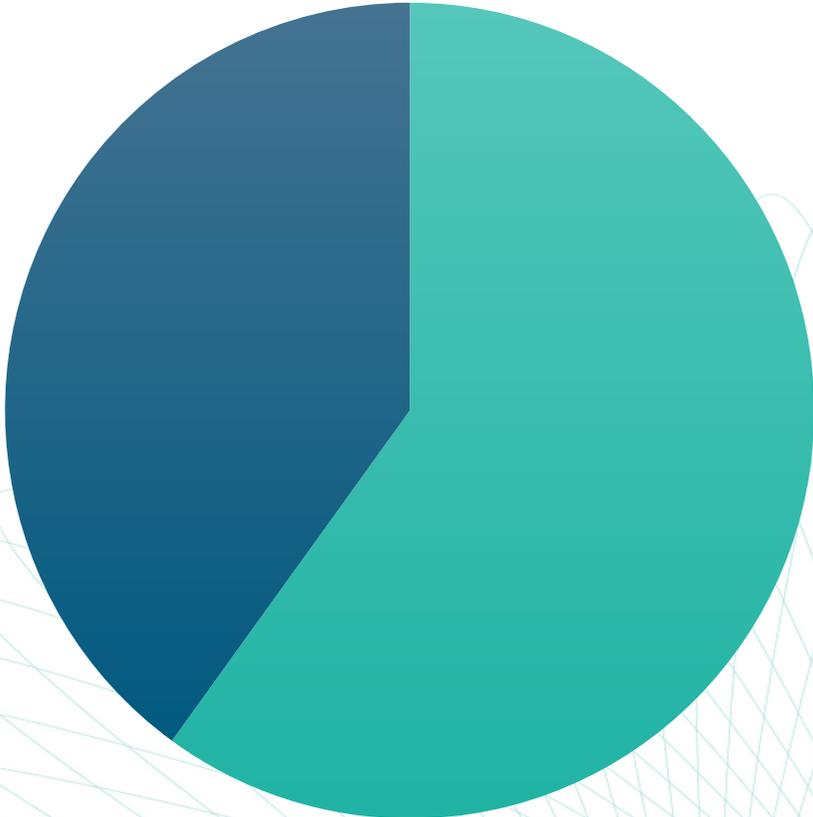


Johnston and Mash Parent Self Efficacy Scale (1989)

Parent Confidence Pre Training



Parent Confidence Post Training



■ high ■ moderate ■ low

Follow-up research with parents

(Telephone interview)

- Amongst all the participants (n=11) who took part in the anxiety training workshops it was reported that all of the parent's had:



- Found the training very helpful



- Used aspects of the training with their child



- Reported their child's levels of anxiety had decreased



- Shared the training with others i.e. family members, friends



- Rated their satisfaction with the overall training as 'very satisfied'



- Reported that they would recommend the training to others

- How confident or empowered did you feel delivering these anxiety strategies?

“I feel much more empowered. As a parent you are seeing what is causing his anxiety. I’m now taking control of the situation now and not dependent on teachers or other experts”.

“Yes I’m definitely more confident. There is more open communication at home now and I don’t try to be this super human person who is calm all the time, happy all the time and who is in control of everything”.

- Overall what impact has the training you received had upon your child, you and your family?

“I am more confident that I am able to manage better. My son still takes time to grasp things but that is the way he is but I believe he will get there and will benefit from the training”

“It’s been really positive. It has highlighted sometimes that I need to take a step back and revisit strategies. My son is now taking responsibility for himself and is doing things independently and is now coming to me and my husband for support so it has empowered him”

Limitations

- Small sample size
- Parents of boys with ASD - may not be reflective of all individuals across the autism spectrum.
- Low coverage of anxiety within the NCBRF (1995), questionnaire - may not be a sensitive measure of anxiety in CYP with autism.
- Parental bias

Summary of Findings

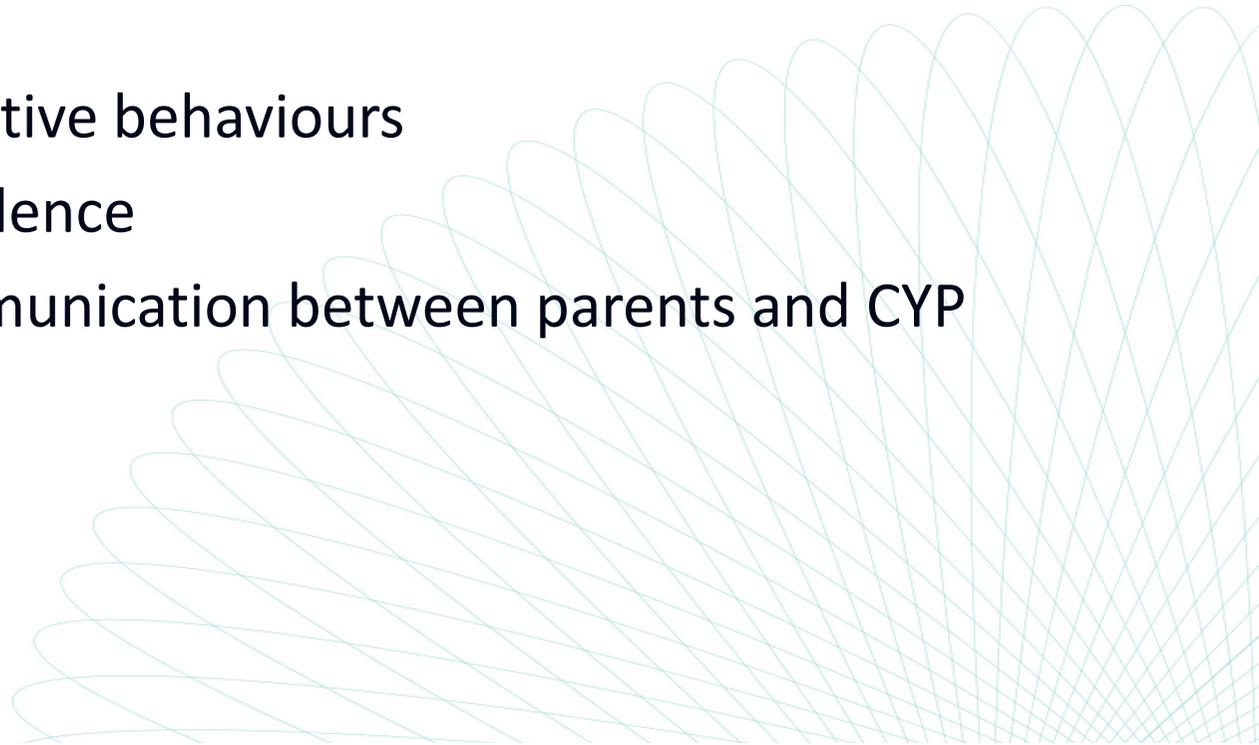
- A positive impact on uncertainty levels for CYP – parents reported 60% decrease for their child.
- Evident increase in adaptive and social behaviour for 80% of CYP and a marked reduction in problem behaviour for 40%- suggesting CYP were empowered to recognise and manage their anxiety.
- Previous research highlights that training for parents of CYP with autism is effective in decreasing problem behaviours (Matson et al., 2009; Crone and Mehta., 2016)

Summary of Findings

- **Anxiety management training had a positive impact on parental feelings of efficacy in relation to them managing their CYP's anxiety.**
 - Schultz et al (2011) found ... parents have less stress while showing an increased level of parenting competency through participation in intervention procedures for their CYP with autism.
- **Parental training, as a method of support in reducing the anxiety experienced by CYP with autism is beneficial.**
 - training for parents of CYP with autism is effective in decreasing problem behaviours (Matson et al.,2009; Crone and Mehta., 2016)

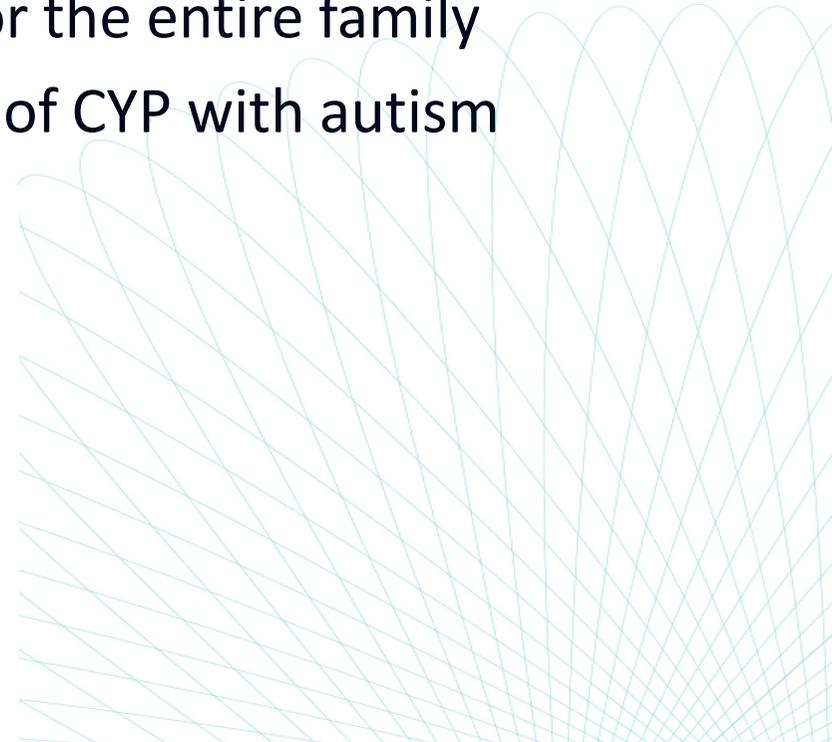
Conclusion

- Parental training, as a method of support in reducing the anxiety experienced by CYP with autism:
 - Increased parental knowledge, awareness and application of appropriate strategies
 - Effectively increased positive behaviours
 - Increased parental confidence
 - Offered more open communication between parents and CYP with autism



Future Research

- Employing a larger sample size including parents of CYP with autism of both genders
- Consider the impact of anxiety training for the entire family
- Including a broader age and ability range of CYP with autism



Research indicates that Parental Training



- Provides support (McConachie & Diggle, 2007)
- Effective for reducing disruptive behaviour (Posterino et al., 2017)
- Increase confidence and reduce stress (Montes and Halterman, 2007)

Implications

For Practice

- Parental training as a mode of supporting CYP with autism may be beneficial.
- Every CYP with autism is different one strategy does not fit all or every situation.
- Involving CYP in the training and intervention process can reap benefits when employing supportive strategies.

For Policy

- Wider availability of parental training offered following assessment
- Cost effective -considering demand on professional waiting lists and current economic cuts



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