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Parent training as a means of reducing anxiety in autistic children

Anxiety is estimated to affect at least 40% of autistic individuals (van Steensel et al. 2011) and is a prevalent problem for autistic child and young people (CYP) (White et al., 2009). The difficulty facing parents and professionals alike is that demand for support with anxiety tends to outweigh specialist provision (The National Autistic Society, 2010).

Middletown Centre for Autism undertook a study to determine the effectiveness of parental training as a method of support in reducing the anxiety experienced by autistic CYP, and to consider the impact of anxiety management training on parental feelings of effectiveness in managing their CYP's anxiety.

Research has shown that parental training:

- is cost effective (Matson et al., 2009)
- increases parental confidence and reduces stress (Montes & Halterman, 2007)
- effectively reduces disruptive behaviours (Postorino et al., 2017) and anxiety for autistic individuals (Schleismann & Gillis 2011).

Methods

Middletown Centre for Autism is the main provider of parental autism training across Ireland and Northern Ireland. Working in partnership with the University of Reading, the Centre delivered a series of five workshops for parents focusing on evidence-based strategies to reduce anxiety. Four of the workshops had been developed by Dr Fiona Knott at the University of Reading; Middletown Centre developed an additional sensory workshop.

Parents of school aged children (10 – 18 years) with a diagnosis of autism and who were attending mainstream school were recruited from across Ireland and Northern Ireland. Parents attended five workshops, completed weekly homework and three pre and post questionnaires, ⁱ and participated in a follow up telephone interview at the end of the intervention.

The following sections outline the workshops and their content.

Session 1. Introduction to anxiety

Anxiety can cause physical, psychological, emotional and behavioural symptoms such as:

- nausea, headaches, sweating, muscle tension, fatigue
- feelings of fear, worry, dread or irritability
- catastrophic predictions and expectations of failure to cope
- avoidance or hypervigilance and checking
- increased repetitive or obsessive behaviours.

The cause or causes of anxiety can be difficult to pinpoint. [Anxiety UK](#) suggest imagining anxiety as a bucket of water; an accumulation of small everyday stresses or something very stressful will fill the bucket or even make it overflow. Therefore, it is essential to invest time figuring out the personal causes of anxiety and identifying strategies to effectively relieve, reduce or avoid the rush of anxiety.

As part of the session, parents discussed some of the difficulties their children experienced because of anxiety such as:

- avoiding or withdrawing from school
- dictating family activities
- engaging in self-harm.

Parents were encouraged to take note of any incidents of behaviours such as anger outbursts, withdrawal, increased self-stimulatory behaviour and general indicators of anxiety and to think about the events leading up to such behaviours.

Session 2. Action

Though the cause of anxiety can be highly individual, unfamiliar or unexpected changes to routine, environment or social exchanges, sensory challenges and fears or phobias have all been areas noted as causing anxiety for autistic CYP. As part of the second session, results from the three pre-intervention questionnaires were used to focus parent's attention on areas that caused their child anxiety. Useful strategies were also discussed, such as:

- educating CYP on emotions
- identifying emotions and levels of distress/ anxiety (visuals can help)
- educating CYP about anxiety and how it physically feels e.g. palms get sweaty, heart beats faster, breathing changes etc.

Session 3. Sensory Issues

Sensory issues can impact on an individual's ability to engage fully in daily life (Koenig & Rudney, 2010), their relationships (Test et al., 2014) and it can affect the development of functional life skills (Carter et al 2013).

Parents were supported to identify their child's sensory needs and the impact certain environments had on their anxiety. The relationship between sensory issues and anxiety is not hard to comprehend; for autistic CYP exposure to certain sensory stimulation can cause similar symptoms to anxiety, and evolve into a 'chicken and egg' type spiral (Green & Ben-Sasson., 2010).

During this session parents were advised on age appropriate sensory strategies all of which are available to view on the free 'sensory resource' via the Middletown Centre for Autism [sensory processing resource](#).

Session 4. Strategies for managing anxiety

During this session parents were introduced to practical strategies to help manage anxiety. Anxiety management strategies should be individualised to the unique needs of each CYP and are likely to consist of a combination of proactive and reactive strategies, such as for example:

- removing or reducing the source of anxiety
- calm box/ sensory toolkit /sensory activities
- visual communication supports (to prepare CYP; to give choice of and prompt appropriate responses)
- progressive muscle relaxation and breathing exercises
- teaching emotional regulation
- [The Incredible 5-Point Scale](#).

Parents were also given tips on tailoring strategies to the individual needs of CYP using case studies specific to the Centre. All strategies mentioned, and many others, are available via the [Middletown Centre for Autism website](#).

Session 5. De-sensitising strategies

The final session involved using elements of cognitive behavioural therapy (CBT) and de-sensitisation therapy to reduce the anxiety associated with 'triggers'. This session explored how negative thoughts contribute to anxiety, and how people behave and react in situations that trigger anxiety.

The parents were encouraged to discuss how they could support their child.

- Using diaries to write about or record the fear/anxiety trigger, reflect on that and then discuss positive ways of tackling that situation in the future.
- Researching new places/events/environments with the CYP well in advance.
- Planning and deciding together how the CYP will communicate if things are getting too much and what will happen next. Prompt cards and smart phones can be used to record this.
- Desensitisation techniques involve gradual, predicted and consented exposure to the anxiety trigger. We used 'fear ladders', which visually breakdown the fear/trigger into small steps from the easiest exposure to the most difficult.
- Celebrating all success (however minor).

Parents were also given information on local support groups and additional services provided by Middletown Centre for Autism such as training and online courses.

Results

Eight of the ten parents who attended the five sessions had received no anxiety training prior to the study. The parental training workshops had a positive impact in reducing anxiety for the CYP; 60% of the parents reported a decrease in their child's level of uncertainty related to anxiety; and increased adaptive and social behaviours for 80% of the CYP. A marked reduction in 'difficult behaviours' was evident for 40% of the CYP.

Results suggest that CYP were empowered to recognise and manage their anxiety. Additionally, all the parents reported increased knowledge of, and understanding in applying appropriate strategies, and they would recommend the training to others.

"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".

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

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Author: Dr Fiona McCaffrey, Dr Rachel Ferguson
Organisation: Middletown Centre for Autism
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ⁱ Anxiety Scale for Children – Autism Spectrum Disorder – Parent version (ASC-ASD -P) 2015; Nisonger Child Behaviour Rating Scale (NCBRF) 1995; Johnston and Mash Parent Self-Efficacy Scale 1989