CHAPTER 10

SUPPORTING FAMILIES

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OVERVIEW

This chapter focuses on supporting the families of children and young people with ID, autism and anxiety. A parent support model for managing the anxiety of this group will be explored, and its implementation on a small group of parents will be discussed.

Learning objectives:

- To understand about the co-morbidity of ID, autism and anxiety.
- To develop a programme of anxiety management strategy.
- To examine the effectiveness of a parental programme.

INTRODUCTION

There is growing evidence that children with autism and ID have higher rates of co-morbid psychiatric disorders than typically developing children, including anxiety disorders and depression (Brown, 2000; Brereton *et al*, 2006). Studies show that, for both adults and adolescents, those with both ID and autism have higher levels of anxiety than groups with ID but not autism (Hill & Furnniss, 2006; Bradley *et al*, 2004). In young people with autism, anxiety is significantly higher than in young people with ID without autism (Brereton *et al*, 2006). In fact, epidemiological studies estimate that the prevalence of anxiety in children and young people with autism ranges from 13.6% to 84% (Muris & Steernman, 1998; Gillott *et al*, 2001; Sukhodolsky *et al*, 2008; Simmonoff *et al*, 2008).

It is important to note that anxiety disorder is more likely to increase during the transition from childhood to teenager, and this is a stage when they are most vulnerable to develop mental health problems in general (FPLD, 2005). Growing up is a very difficult and stressful period for many young people and adolescents, and it may be even more stressful for young people with ID who are not fully aware of the process of change and who are faced with making choices about the future and their aspirations (Raghavan & Pawson, 2008). They are, for example, more likely to be worried about bodily appearance or about leaving home than their peers (Graham, 1991), and there are other changes that can affect them, especially the loss of friends or social networks, which can put them at greater risk of developing mental health problems (Raghavan & Pawson, 2008). Furthermore, it is also possible that as children grow older they are better able to express their emotions and their parents become better observers of anxiety disorder, or these symptoms become more prominent in the home (Weisbrot *et al*, 2005) leading to a greater incidence of reported cases than in younger children.

It is recognised that emotional problems such as anxiety disorder occur frequently in young people with autism as a consequence of the features that define the condition (Leyfer et al. 2006), such as low intellectual abilities, poor communication skills, a lack of social and cognitive resources and poor coping skills (particularly for higher functioning individuals who are more aware of the difficulties and challenges they face). For example, features such as low intellectual abilities and poor cognitive skills are more likely to lead to low self-esteem (Henry & Crabbe, 2002), a lack of communication skills may result in greater difficulties in discussing or dismissing fears, resulting in over-generalisation (Smiley, 2005), and poor coping skills may result in greater anxiety as children face unfamiliar problem-solving tasks (Henry & Crabbe, 2002). Furthermore, other deficits associated with autism, such as difficulty in understanding emotions and interpersonal relations, along with misinterpretation of social cues, may also lead to anxiety disorder.

It is also important to note that sensory integration affects a significant number of individuals with autism (Rogers *et al*, 2003) and research shows that sensory processing is related to autism symptoms and anxiety disorder. People with autism often experience forms of sensory sensitivity, either hyper-sensitive or hypo-sensitive (Aron & Aron, 1997), which can impact greatly on their behaviour and contribute to anxiety disorder (Sofronoff *et al*, 2005).

In brief, all of the above factors suggest that the co-morbidity of ID and autism results in an increased vulnerability to anxiety disorder.

The impact on families

Experiencing significant levels of anxiety can be disabling for children with autism and ID, resulting in negative consequences for both the children themselves and their families. Anxiety may cause considerable distress and interfere with a child's daily activities (Muris & Steernman, 1998; Bellini, 2004) and further impede their interactions with others (Rapee *et al*, 2008), and evidence shows that the children's emotional and behavioural difficulties has a significant impact on family well-being (Herring *et al*, 2006; Tehee *et al*, 2009). In fact, caring for a child with autism and ID can make parents themselves more vulnerable to developing mental health disorders, such as stress or depression, than other parents (Hastings *et al*, 2006; Heiman, 2002; Grant *et al*, 1998).

Parents are generally considered to be a child's most important resource, and they have a vital role to play in providing the support that a child needs. However, we often tend to ignore or marginalise the role of family carers in interventions at home, but in fact parental involvement in interventions with children with autism and/or ID is an important ingredient in ensuring positive outcomes (Diggle *et al*, 2008; Ozonoff & Cathcart, 1998). It is suggested that majority of family carers can give better care than anyone else, and Grant *et al* (1998) point out that '*services have many things to learn from family caregivers*' (pp46).

Despite this, there is little published research attempting to develop parental interventions that address anxiety in children and young people who are diagnosed with both autism and ID. Almost all published studies in this area address psychosocial interventions (eg. Chalfant *et al*, 2007; Reaven & Hepburn, 2003; Sofronoff *et al*, 2005). Given the importance of involving parents for supporting their children, and the fact that parental support has received little attention in the management of anxiety in children and young people with autism and ID, this chapter will examine a family carer intervention model known as the Calm Child Programme, for children and young people with ID, autism and anxiety disorders.

Calm child programme

There is an abundance of literature about family intervention and early intervention programmes for autism in children, such as the Son–Rise programme and Applied Behaviour Analysis (ABA). These programmes encourage many positive improvements for families, such as enhancing parents' confidence, relieving parental stress, cost effectiveness, enhancing the capacity of the family, and increasing quality of life (Grant *et al*, 1998).

The Calm Child Programme (CCP) was specifically designed for parents who have a child or adolescent with ID and autism and was developed in consultation with parents, teachers and a group of professionals working in the field of child and adolescent mental health. A study was conducted with these groups to explore the range of anxiety management strategies used by parents and teachers. These strategies were then further discussed with professionals to develop a model of the types of interventions that are useful and that can easily be implemented by parents, to provide them with effective and practical management strategies to help children and young people manage and cope with anxiety.

PROGRAM CONTENT AND COMPONENTS

The programme consists of three types of management strategies that, at different levels, were intended to complement each other:

- **Proactive strategies:** these aim at crisis prevention, were recommended for use on a daily basis to prevent triggering anxiety by using visual schedules, talking and explaining, relaxation techniques and physical activities.
- **Communication strategies:** these aim to communicate with the child or young person when they begin to feel anxious using an 'anxiety scale thermometer' that helps to identify the level of a child's anxiety so that parents can implement appropriate strategies from the 'traffic light system' used by the CCP.
- **Reactive strategies:** this are designed to manage the child's anxiety, using distraction, quiet-time, fun activities and comfort strategies. These are recommended when a child shows behaviours related to severe anxiety.

The Calm Child Programme consists of two parts; part 1 provides basic information about autism and anxiety, and part 2 covers simple anxiety management strategies. Part 1 therefore provides the following information.

Part 1: What do you know about autism, ID, and anxiety?

Children with autism show three types of symptoms:

- impaired social interaction
- problems with verbal and nonverbal communication and imagination
- unusual or severely limited activities and interests.

ID includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and a reduced ability to cope independently (impaired social functioning) that started before adulthood, with a lasting effect on development.

What is anxiety?

All children experience some anxiety. This is normal and expected, but when it interrupts a child's normal activities such as attending school and making friends or sleeping, and has a bad impact overall on his adaptation behaviour, such anxiety becomes a problem.

How do children with autism spectrum disorders show anxiety?

Children and young people with autism experience a wide variety of fears and anxiety.

Children are all different, and the symptoms of anxiety may present in different ways, including:

- feeling very hot or sweaty
- crying a lot
- shaking hands and legs
- feeling breathless
- finding it difficult to sit still
- feeling panicky
- feeling funny in the stomach.

Children with autism also feel worried or nervous in different ways. Here are some words and phrases that children with autism and ID might use to explain their fears and worries:

- stressed
- things wrong with me
- fed up
- frightened
- in a temper
- in a huff

What can cause anxiety?

There are lots of reasons why children and young people with ID and autism may be at risk of getting nervous:

- there is a change in daily routine
- they meet new people
- someone comes to their house
- they are in busy or crowded places
- they facing new or un-expected situations
- they worry about their family, future or their mental health
- they have difficulties understanding the world and communicating with others
- they are unable to communicate what they want to say.

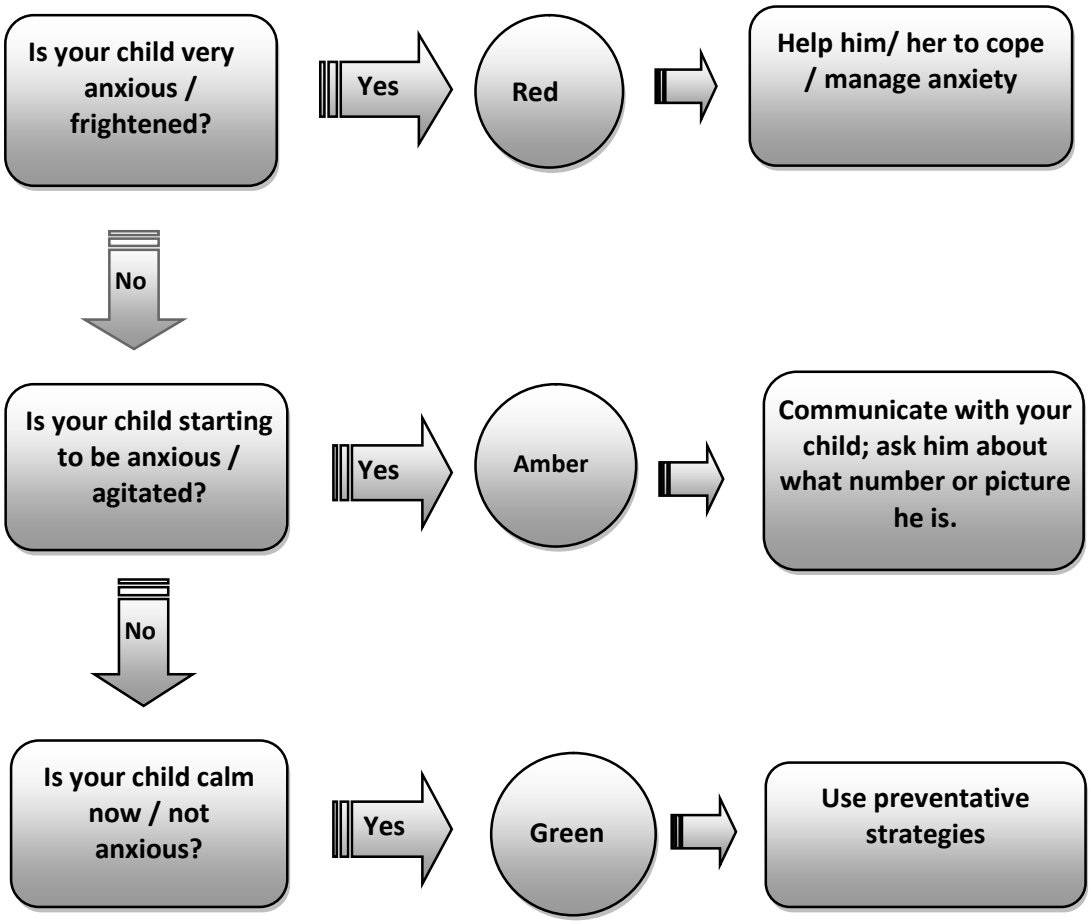
Part 2: Anxiety management strategies

What are anxiety management strategies?

Anxiety management strategies involve techniques that parents and teachers can use to help children with autism and ID to cope better with their worries and fears. The information below demonstrates some management strategies that parents and teachers think are useful for managing anxiety in children and young people with autism. Professionals, such as psychiatrists, psychologists, nurses and social workers, have also seen these strategies and think they could be useful.

The CCP operates a ‘traffic light’ system to determine a child’s anxiety level and how a parent can help them to cope with each level. In the following three sections you will find a traffic system: we will go ahead with the GREEN colour that refers to strategies you might use most of the time when your child is OK, then the AMBER, which means strategies you might use once you notice your son’s anxiety, and giving you what level of anxiety he is. Finally, the RED colour you should use when he is anxious (Figure 1).

Figure 1: Traffic Light system for identification of anxiety



1. Daily life strategies

The Green light strategy is a proactive approach which aims at crisis prevention. The focus is on supporting your child to remain calm and for you to be one step ahead. You might need to use these ideas most of the time, day by day in order to reduce your child's anxiety. Here are some recommended ideas:

- **Visual schedule**

The visual schedule or time table uses pictures as a means to support your child to cope with change. Children with autism are more sensitive to any change in their daily routine. So this visual time table helps to reduce anxiety because it helps them to understand what they are going to do during their day. A visual timetable makes time concrete, allows a child to see time passing, and to see plans for the future.

For most children, arrange the timetable from left to right. For some young children, a top to bottom format may be more understandable.

- **Talking and explaining**

Talk to your child in a very simple language constantly about what he is going to do. Keep the information very simple. Talk about the situation and let your child know what is happening. For example, suggestions like, we are now eating a snack, and then in 5 minutes we will play. In ½ hour we will put on our coat and shoes on and we will get in the car. The basic rule is to be clear, concise, and consistent.

Explain in advance of any out of routine events, like holidays using brochures and leaflets for the place you are going to visit, as a trip with the school, or school shopping trips.

- **Regular physical activities**

Physical activity is very good for your son/ daughter particularly if they are very agitated. Activities that other parents have found helpful are:

- Get outside and do some exercise, such as running in the garden, swinging.
- Going for a walk, a short walk in the fresh air can be helping him feel good, or perhaps for a long walk with the dog.
- Jumping on a trampoline.
- Special regular activities: e.g. swimming, Karate, riding horse, football, dancing.

- **Relaxation**

Help your child to relax. Firstly it is important to create a relaxing environment - choose a comfortable, quiet and peaceful room. It may be possible to teach your child how to relax as a coping skill when he becomes agitated or angry. There are many ways to help him to relax including:

- Breathing technique:

For example deep breathing, to take time to breathe slowly and deeply and count 1 to 10, as this can help them to feel calm. Also practice some breathing exercise, for example, ask your child to pretend that he is blowing a balloon and then let the balloon out.

- Listening to relaxing music:

Music can stimulate and develop more meaningful and playful communication in people with autism. Music can also play an important role for children with autism in developing positive interactions. For example you can use calming music every time before bedtime.

- Reading books: e.g., book explaining to the child how s/he can express their feeling.
- Warm bath in low lighting: may help your child to feel calmer.

1. **Communicate with your child's anxiety!**

It is essential to talk to the child and to gain his/her view of the situation. Children may be able describe their fears or anxiety and the situations which give rise to them. This communication is likely to be helpful. If you noticed your son / daughter appeared worried or agitated, then there is an opportunity to start to communicate with him/ her. So you might tell him that you notice he looks anxious. For example, "Are you alright?" Or "How do you feel?"

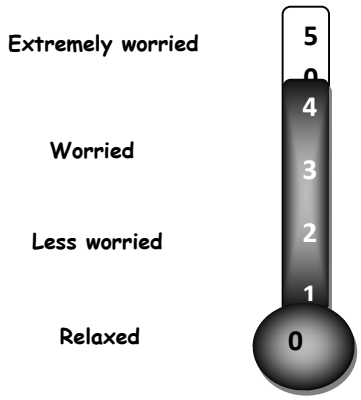
Here are some ways to help your child to tell you more

- **Thermometer approach**

You may present the thermometer of anxiety rating scale to the child and ask him to let you know which number he is (see Figure 2).

E.g. how worried are you? Can you show me? Are you a 2 or a 3?

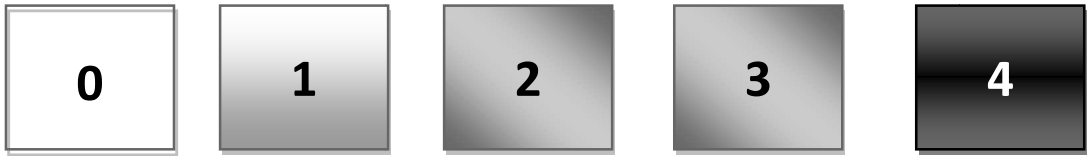
Figure 2: Anxiety Thermometer



- **Anxiety pictures/ Numbers**

You can use pictures to help your child tell you about their feelings. You might ask your child to draw pictures that make sense to them.

Example: 1



Example: 2

3. REACTIVE STRATEGIES

When your child or young person is agitated or feeling anxious, there are a number of ways to help them to cope with anxiety.

- Have a little fun

Having fun is a great way to increase good feeling and release tension. Getting in touch with fun and play is often easier for children than for adolescents. Sharing fun with your son/ daughter is often helpful to release his fears or worries, for example, play his favourite games, try some painting. Children can express their feeling by drawing.

- Special interest (distractive)

One way of helping your child to cope with his anxiety is to make use of his particular interest. When you find your son/ daughter agitated ignore the situation and try to distract him before escalating his anxiety level. The trick here is to let him/her do something he enjoys e.g., watching his favourites DVDs, playing favourite games, jumping, drawing, feeding the birds, his favourite toy.

"e.g., it was (good) to distract (child) by watching videos, he was really extremely calm, you can easy pick him up." Mum

- Quiet- time out

Time out gives your child the chance to have time to manage themselves. This gives him the chance to calm down. The time given should be kept to 1to 3 minute for each episode although this can be repeated. A quiet stimulation-free spot is a good choice. Some children ask for time-out for themselves.

e.g." the best thing is to keep him away, after a while; 20-30 minutes, this calmed him down- as though nothing happened" Mum

- Comfort strategy (reassurance & cuddling)

Parents can offer physical expressions of love for their child to help to calm them down. Simply placing your hands on the back or holding hands can be very relaxing. You will know what areas are most sensitive for your child and so avoid them. You may need to find out what sort of touch or holding gives most comfort.

Implementation of the CCP

In order to implement the CCP, a pilot study was conducted over three months with seven families with children with autism and ID to evaluate its use. First, a meeting was organised with parents in order to explain about the CCP information pack. This information pack included:

- the CCP itself
- the Glasgow Anxiety Scale (GAS ID) (Mindham & Espie, 2003),
- a parents' dairy
- consent forms
- an example of a visual schedule.

All participating parents gave their written consent for their participation before the start of the programme, and they completed the GAS-ID. They were then asked to monitor their children on a daily basis and record in a diary the levels of anxiety observed, any related behaviours and which of the above strategies they used to address the problems and their various outcomes. Parents were contacted every fortnight to get an update on how they were experiencing the CCP. At the end of the implementation period of three months, parents completed another GAS-ID about their child and an evaluation form about the programme. A focus group was then organised to discuss the usefulness of using the various management strategies.

85% of participating children and young people showed statistically significant improvements in anxiety levels between pre- and post-test. Furthermore, parents who implemented the programme were more likely to manage their child's anxiety more positively.

The focus group emphasised the effectiveness of the CCP in managing children's anxiety, and it was discovered that the most effective strategies were talking and explaining, physical activities and distraction. The majority of parents used a combination of these different strategies to manage the child's anxiety, however it is interesting that the parents also reported that the children began to self-manage using the same strategies when they were feeling stressed or worried.

A strong theme that emerged from the CCP was that it improved parents' confidence and increased their knowledge and skills in recognising and managing anxiety. The CCP supports parents to manage the anxiety of children and young people with autism and ID, enhancing family protective factors and reducing risk factors associated with severe emotional difficulties. The parental programme can also help reduce parents' anxiety, and the high levels of stress they may experience, especially within the parenting role (Tehee *et al*, 2009; White & Hastings, 2004). Providing parents with a practical and appropriate programme of parental strategies helps to strengthen the family's capacity to meet the needs of the child (Wang *et al*, 2006). Prevention programmes starting in early childhood can improve outcomes for children and families and providing a programme to support parents to manage their child's anxiety is likely to reduce the demand for services, both for the child and the parent, resulting in a reduction in service costs and workloads for professionals (Mudford *et al*, 2001; Smith *et al*, 2000).

CONCLUSION

A simple and easy to use intervention strategy, the CCP was developed for addressing anxiety in children and young people with autism and ID. The implementation of the CCP showed that management strategies and interventions targeting children and young people with autism and ID were effective, and that involving the parents in interventions is a successful model for caring with this group. Supporting families in the implementation of intervention strategies will put them in control and develop their confidence when caring for children with ID, autism and anxiety.

Summary

1. Children with intellectual disability and autism experience higher levels of anxiety. This impacts the family wellbeing.
2. An intervention strategy known as the CALM Child programme developed for parents to manage the anxiety of their children with ID and autism. A pilot study of this intervention strategy indicates significant improvement of anxiety levels of children with ID and autism.

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