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## **Anxiety and Autism: A Brief Review of Research and Autobiographical Literature**

**This article contains an overview of some of the literature published over the past decade focusing on autism and anxiety. It also contains information from autobiographical accounts of people with autism. Cognitively based interventions for anxiety in autism are discussed. The ‘Emotional Toolkit’, an autism specific cognitively based approach to managing anxiety is highlighted as effectively reducing parent reported anxiety in young people with autism.**

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### **INTRODUCTION**

There is much research and anecdotal evidence suggesting a high prevalence of anxiety in people with autism (Kim, Szatmari, Bryson, Striener and Wilson, 2000; National Autistic Society, 2010). Research in the area focuses on the prevalence of anxiety in people with autism and also on treatment programmes that are effective for them. Autobiographical accounts relate the individual nature and experience of anxiety as well as some personal coping strategies.

In this review research and autobiographical evidence will be examined and broad themes for intervention and support strategies will be highlighted. The review will examine articles published in peer reviewed journals from 2000-2012 and also the autobiographical accounts of Wendy Lawson, Liane Holliday Willey and Claire Sainsbury. These autobiographical accounts were chosen as they reflect the individual experiences of people living with autism. The authors agreed for their books to be used in a piece of research from which this article has been taken exploring the experience of autism and anxiety.



### **Prevalence of Anxiety in Autism**

Anxiety was described by Kanner (1943) in the initial study of autism. He referred to children presenting as “fearful” (p. 218), “afraid” (p. 222) and “petrified” (p. 223). The UK National Autistic Society in its *You Need to Know* campaign (National Autistic Society, 2010) indicated that eighty-five percent of 455 parents who completed a self-report measure on their child’s mental health reported that their child experienced high levels of anxiety. Simonoff, Pickles, Charman and Chandler (2008) investigated the prevalence of comorbid psychiatric disorders in a sample of 112 children with a confirmed diagnosis of autism and a mean age of eleven and a half years. They found anxiety to be the most common comorbid difficulty amongst the children in their sample with twenty-nine percent of their sample presenting with clinically significant levels of social anxiety disorder with almost forty-two percent overall experiencing high rates of anxiety. The authors highlighted that it was important to assess for both social and generalised anxiety as often people with autism can have an interest in interacting with others, while still having high levels of anxiety about this interaction. They recommended further research into the area of anxiety in autism and specifically the correlation, if any between insights into social deficits and social anxiety. Sukhodolsky, Scahill, Gadow, Arnold, Aman, McDougle, McCracken, Tierney, White, Lecavalier and Vitiello (2008) reported on research conducted using a parental rating anxiety measure. Parents of 171 children with autism rated their child’s anxiety using a recognised anxiety management rating scale (Child and Adolescent Symptom Inventory). They found that forty-three percent of the sample exceeded the cut-off point for an anxiety disorder. They also reported that high levels of anxiety were correlated with the presence of functional language and also higher levels of stereotypical behaviours. They looked specifically at the presentation of social anxiety and reported that those children with higher IQ scores presented with higher levels of social anxiety. This is congruent with the Simonoff et al. (2008) research that indicated a similar relationship between insight into social deficits and social anxiety.

In a review of research studies conducted between 1998 and 2008 White, Oswald, Ollendick and Scahill (2009) noted the prevalence of anxiety in children with autism as being up to eighty-four percent. The authors also discussed a potential relationship between an understanding of the social impairments in autism and social anxiety. They went on to speculate that the co-existence of social impairments and social anxiety can become mutually reinforcing and compound existing anxiety. White et al. also speculated on a possible relationship between cognitive functioning and anxiety citing examples of research that supported the view that the type of anxiety experienced may be related to individual cognitive

ability. Conversely, Kim et al. (2000) drew differing conclusions with their research, which indicated that emotional difficulties were not mediated by cognitive ability. Evidently, more research is needed in this area to fully determine the relationship, if any between cognitive ability and anxiety. The research studies detailed above come from a number of perspectives and employed a range of methodologies including parental report measures, clinical assessments and reviews of literature. Despite the variations in studies the outcomes are clearly agreed that there is a high prevalence of anxiety amongst both children and adults with a diagnosis of autism. Some mediating variables have been discussed including awareness of social deficits and intelligence. The existence of mediating variables indicates that the presence of anxiety can be influenced by individual differences. This is certainly a useful area for future research to investigate as the identification of variables, both individual and external to the person will be useful when developing programmes of intervention. The forthcoming section on autobiographical accounts will provide further discussion on the nature of individual differences in the experience of anxiety.

## AUTOBIOGRAPHICAL ACCOUNTS

This section explores, briefly, the experience of autism and mental health problems as described in three autobiographies of people with autism. These are Wendy Lawson's, *Life behind Glass* (2000), Claire Sainsbury's, *Martian in the Playground* (2009) and Liane Holliday Willey's *Pretending to be Normal* (1999).

Wendy Lawson was diagnosed with autism at age forty after twenty-five years of being misdiagnosed. Lawson was clear about the centrality of her anxiety and in her autobiography she devoted a specific section to anxiety saying:

*Anxiety is perhaps the biggest factor that dominates my everyday life. I get anxious about going to sleep and anxious about being sure I don't miss the time to wake up! It isn't always easy to see my anxiety. I may appear hyped up and excited, so being anxious may not be a consideration. My excitement and enthusiasm can turn rapidly to anxiety and then fear. This in turn can lead to self stimulatory activity (flapping, flicking, rocking, or sucking the roof of my mouth (p. 71).*

Lawson discussed her relationship with her anxiety, speculating that the coping behaviours that she engaged in may not have been that different to neurotypical people but her triggers were highly individual. The triggers could include not seeing the whole picture, not understanding the entire context of situations and

also an inability to cope with change. Lawson explained that when anxious she needed to ask questions repeatedly to check that the answer was always the same.

Claire Sainsbury was diagnosed with autism at age twelve. In her autobiography, Sainsbury described her experience of being a teenager with autism and attending a specialist residential school for children with autism. Sainsbury described in detail her anger outbursts and how these were often related to fear and anxiety:

*If invisible God had been a referee, then my life would be scattered with red cards. If something changed without me knowing, I would go off like a screaming bomb (p. 203).*

Sainsbury experienced fear and disappointment and a sense of isolation, she referred to her “real life” and her “life-lie” (p. 204). She experienced her “life-lie” as being under control while attending college and trying to fit in. Her “real life” was described in terms of having screaming temper outbursts related to anxiety.

Liane Holliday Willey was diagnosed with Pervasive Developmental Disorder at aged four and her autobiography charted her early life and her early career as a university lecturer, her marriage and having a family. Holliday Willey discussed her social anxiety in some detail explaining:

*...human relationships usually take me beyond my limits. They wear me out. They scatter my thoughts. They make me worry about what I have just said and what they have just said and how or if that all fits together ...why do the rules change depending on who the friend turns out to be... well the whole thing drives me to total distraction and anxiety (p. 69).*

There is much more information that could be relayed from autobiographical accounts demonstrating why the personal account should always be taken into consideration. It would not be possible to generalise the diverging personal experiences of the authors quoted above. Lawson explained how her anxiety could be related to excitement and over stimulation; Sainsbury described her anxiety as a feeling of rage; Holliday Willey’s anxiety was related to total confusion in social situations. Assessment and discussing the individual’s experience are key features in helping people with autism manage their anxiety.

## INTERVENTION AND SUPPORT STRATEGIES

The section begins with a brief discussion on the research into cognitively based interventions for anxiety in autism. It then addresses an autism specific cognitively based approach to managing anxiety.

White, Oswald, Ollendick and Scahill (2009) reviewed forty articles exploring cognitive behavioural therapy approaches (CBT) for children with autism aged between eight and eighteen years. They reported that CBT was the most popular intervention used and its results were largely positive. The most successful application of CBT was where the practitioners were experienced in working with children and young people with autism and employed visual supports, delivering a tailored and augmented approach. Donoghue, Stallard and Kucia (2010) evaluated the impact of CBT on anxiety in autism. They identified a series of practice points that were employed in successful CBT approaches:

- working in partnership with the child and family
- using strategies that were appropriate for the child's developmental level
- using empathy
- using a creative approach (for example using favoured activities and books, music and drama)
- encouraging investigation and an approach that the child or young person enjoys.

Moree and Thompson (2010) provided a thorough exploration of a cognitive approach in their review of modification trends in CBT. They highlighted that CBT based approaches were most successfully used in children and young people who had a high level of functioning, and that similar to the findings of Donoghue et al. (2010), modification of the CBT approach is very much based on the individual needs of the child or young person. They identified that using visual material in a highly tailored approach was the most successful CBT based approach.

An example of a CBT based approach is that of Sofronoff, Attwood, Hinton and Levin (2007) and Attwood and Sofronoff (2013) who described a successful cognitively based anger and anxiety management programme, the 'Emotional Toolkit'. Their approach demonstrating an effective anxiety management approach (Sofronoff et al.; Scarpa and Reyes, 2011; Attwood and Sofronoff) includes all of the components of a successful CBT programme as described by Moree and Thompson (2010) in their review of forty CBT based programmes for children with autism. These components are:

- using the child's specific interest
- incorporating the child's parents in some way
- developing an understanding of difficulties directly related to autism.

The research cited above indicated that the 'Emotional Toolkit' approach resulted in a significant reduction in anxiety symptoms as rated by parents. The tool kit is an example of one of many similar CBT programmes that are available to address anxiety in children. It is of particular significance in the current review as it is an autism specific intervention and was developed exclusively for the needs of children and young people with autism.

### **The Emotional Toolkit**

The programme consists of six two-hour sessions that can be delivered by teachers, therapists or parents and commences with a session on 'affective education'. In affective education the children learn about their emotions and are encouraged to describe and explore different emotions, for example, happiness, anger or anxiety. Children are encouraged to explore one emotion at a time and use them as the basis for projects on individual feelings. The children are then encouraged to use a gauge of their feelings, for example, using a 'feelings thermometer' in order to understand and communicate the intense or fleeting nature of feelings.

The children are then encouraged to explore how they think about things and how this might impact on their mood and on their current and future behaviour. Different methods can be used in order to identify and change thinking styles, for example, comic strips, role play and visuals. The children are encouraged to identify faulty thinking and replace current thinking styles with more positive and helpful beliefs. An example of this would be having a 'reality check' or trying to get incidents and issues in perspective.

The focus of the sessions finally shifts to the development of an 'Emotional Toolkit'; the children are encouraged to imagine a toolkit and the tools that it might contain. This idea is developed into the concept of 'having a tool to fix a feeling'. For example, a hammer may be conceptualised as a physical tool and compared to doing physical exercise to release tension and the energy generated by an anxiety response to fearful stimuli. Children can detail physical release tools like a trampoline, massage, or going for a walk or run and these tools become part of the child's toolkit.

The 'Emotional Toolkit' is gradually populated with a range of useful strategies to address anxiety in the guise of social, thinking, physical, relaxation and special

interest 'tools'. As discussed above, this approach has been demonstrated to be an effective approach for managing anxiety (Sofronoff et al., 2007; Scarpa and Reyes, 2011; Attwood and Sofronoff, 2013). The toolkit was shown to be effective in reducing parent reported anxiety both at the time of the intervention and also in a follow-up six months later (Sofronoff et al.).

### **The Cognitive Affective Training Kit**

The authors of the toolkit (Sofronoff et al., 2007) have recently developed the Cognitive Affective Training kit (CAT-kit). This is another autism specific intervention that is based in CBT theory. The CAT-kit consists of a collection of resources including worksheets, visuals and an interactive DVD that promotes communication about and understanding of emotions and thinking. Research is currently being conducted into the efficacy of the CAT-kit approach (Kuroda, Kawakub, Kuwabara, Yokoyama, Kano and Kamio, 2013). However, it is currently a popular resource amongst practitioners and is recommended by the National Autistic Society as a useful intervention for children and young people with autism who experience high levels of anxiety.

### **CONCLUSION**

This review was brief and there is a need for a comprehensive assimilation of information from both empirical and anecdotal accounts of anxiety in people with autism to fully explore the phenomenon. What was demonstrated in this review was the growing body of evidence, using a range of methodologies that illustrates the prevalence of anxiety in people with autism. The experience of anxiety is a personal and individual one and any intervention addressing this anxiety should begin with a thorough assessment. Finally, there are interventions that have been shown to be effective for people with autism. Research reviewed in this article indicated that with some augmentation, CBT approaches could be effective in managing anxiety and also in managing anger. The article briefly outlined the 'Emotional Toolkit' that has been shown to be an effective intervention for managing anxiety and noted that while there are a number of anxiety management interventions for children this is currently the only autism specific intervention. New developments in teaching children to communicate and understand their emotions (for example, the CAT-kit) still have to be assessed. However, anecdotal accounts are positive. Regardless of the approach however, research (White et al., 2009) illustrates that knowledge and understanding of the core impairments of autism and a child centred approach are still the prevailing tools for any practitioner working in the area of autism and anxiety.

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