Volume I

Literature Review and Empirical paper

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Doctorate in Clinical psychology

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Overview

This thesis is submitted as part of the requirements for the Clinical Psychology Doctorate at the school of Clinical Psychology, University of Birmingham. It comprises of academic components of both the clinical work and the research carried out throughout the course.

Volume I comprises of two papers. The first is a review of the literature around the efficacy of Cognitive Behavioural Therapy with individuals with Asperger's Syndrome/High Functioning Autism. studies reviewed involved 'error orientated CBT' only which concentrates more on making psychological changes in terms of addressing thinking errors, such as dysfunctional beliefs and perceptual bias as opposed to behavioural difficulties within the social domain.

Although there was some evidence of effectiveness within the studies it was concluded that due to the paucity of research within the area replications are required before any firm conclusions can be made. Discussion around investigators' adherence to a cognitive behavioural framework is also included.

The second paper is a qualitative study using Interpretative Phenomenological Analysis to explore first hand accounts of adults with Asperger's syndrome in relation to their experiences of being parented during childhood and adolescence. Four main themes were identified: Feeling nurtured and supported, feeling restricted/held back, a sense of loss and appreciation of discipline. This study illustrated how reflective and emotive such individuals can be. It also highlights the importance of early diagnosis and how professionals can focus interventions to support parents in meeting the needs of children and young people with ASD in ways that might facilitate the development of a secure sense of self and psychological well being.

Volume II represents the clinical component of the thesis and comprises of five clinical practice reports which describes clinical work carried out over the three years of training.

The first report is a small scale service evaluation which evaluates pre-diagnostic counselling services for older adults with memory problems. The second report, ‘Psychological models’ formulates the case of a 74 year old woman with depression and anxiety from cognitive behavioural and psychodynamic perspectives. The third report describes a case study of a 34 year old woman with Bulimia Nervosa and a history of childhood sexual abuse. The forth reports ‘Single Case Experimental Design, evaluates a systematic desensitization programme to reduce a fear of dogs in an adolescent with downs syndrome. The fifth report, a case study of behavioural family therapy, was orally presented. The abstract summarizing the case is included here.

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WHAT IS THE EVIDENCE FOR THE EFFECTIVENESS OF COGNITIVE BEHAVIOURAL THERAPY FOR INDIVIDUALS WITH ASPERGER'S SYNDROME AND HIGH FUNCTIONING AUTISM?

LITERATURE REVIEW

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ABSTRACT

There is growing evidence that individuals with Asperger's Syndrome or high functioning autism have higher than expected rates of developing a mental illness, typically anxiety and depression.

Cognitive Behavioural therapy (CBT) is widely considered as the primary psychological treatment for such disorders. The current paper reviews all studies known to have been conducted around the use of CBT with adults and children on the high functioning end of the spectrum (without developmental delay) who have a secondary mood disorder. A particular emphasis was placed on 'error-orientated CBT', which focuses on cognitive change to alleviate emotional and psychological disturbance, as opposed to 'deficit orientated CBT', which is concerned with teaching skills and is largely derived from the self instructional literature.

Results reported suggest that CBT can be effective for adults and children with AS/HFA in the reduction of symptoms related to mental health difficulties. However, due to the paucity of research available particularly for adults, and methodological limitations, conclusions drawn on their basis must be tentative. Further research into this area is critical if a more robust conclusion of efficacy is to be made.

A Note on Terminology

The relatively new diagnosis of Aspergers Syndrome (AS), a form of autistic spectrum disorder (ASD), is widely compared with High Functioning Autism (HFA), a more established sub category. Since it's introduction to the DSM-IV (American Psychiatric Association, 1994), and subsequently the ICD-10, (1992), there has been much empirical debate around whether there are any qualitative differences between AS and HFA with some authorities stating that Asperger's is simply 'high-IQ autism', while others argue the case for it to be recognized as a sub category in its own right. Ozonoff and Griffith (2000) provide a comprehensive review of the literature from both sides of the debate, which is outside the scope of this review.

The National Autistic Society (2005) concludes that "the fundamental presentation is largely the same" a view shared by Attwood (2006). For the purpose of this report, it is considered that there is sufficient empirical evidence to suggest that the two subcategories are sufficiently similar for joint inclusion. Consequently, unless otherwise indicated the writer will use the term AS to include all persons who present on the autistic spectrum who have verbal and intellectual ability within average to above average range.

1. Introduction

Asperger's Syndrome (AS), first introduced by Wing (1981), is charactorised by two principal areas of deficits: i) social interaction (significant difficulties with: eye contact; developing peer relationships; spontaneous shared enjoyment of interests and achievements; social or emotional reciprocity) and ii) restricted, repetitive and stereotyped patterns of behaviour, interests and activities (e.g.: stereotyped patterns and motor mannerisms, rigid adherence to non functional routines, persistent preoccupation with parts of object); (American Psychiatric Association, 2000).

Although research into the adult population is limited, there is increasing evidence that individuals with AS have higher than expected rates of developing a mental illness. Current research within the adolescent population has found that around 65% of adolescents with AS have a range of anxiety disorders (e.g. Gillot, Furniss, & Walter 2001); depression (e.g. Perry Marston, Hinder, Munden & Roy, 2001) and even delusional disorders and paranoia (Blackshaw, Kinderman, Hare, and Hatton, 2001).

Due to the multifaceted nature of AS, symptom profiles are very much idiosyncratic and can often mimic other disorders such as anxiety, particularly OCD and social phobia and mood disorders, including bipolar. However, there are many cases where adults and children on the spectrum can present with true co-morbid mental health difficulties.

1.1 Understanding the risk of people with AS developing mental health difficulties: A conceptual model

Individuals with AS typically have deficits in social cognition, that is, the ability to process social information about themselves and others within the context of their social world. A significant body of research within this area has focused on Theory of Mind, which is defined as the ability to infer the internal mental state of others, (Rutherford, Baron-Cohen, and Wheelwright, 2002). This can manifest as difficulties in identifying emotional expressions and reading social situations. Such fundamental social deficits can severely impair the individual's ability to develop and maintain social relationships, which can have a significant impact on self- esteem and emotional well-being.

Research into executive functioning has found a range of deficits that suggest characteristics such as disinhibition, impulsivity and a relative lack of insight, which may impact on general levels of functioning (Ozonoff and McEvoy; 1994; Pennington and Ozonoff, 1996).

Gaus (2007) implies that due to an idiosyncratic way of processing social and nonsocial information there is an intrinsic vulnerability to developing maladaptive schemas, which are defined as cognitive structures that influence the interpretation of events and experiences. These are thought to be based on *core beliefs*, which are rigid, inflexible beliefs developed and learned early on in life through experiences such as significant events and relationships (Beck, 1976).

The relationship between cognitive dysfunctions associated with AS and the problems commonly reported, are illustrated in a model presented by Gaus and feature vulnerability points for the development of maladaptive schemas (see Fig 1). The model hypothesizes how difficulties are caused by neurological differences in the way that social and non social information are processed (Klin, Jones, Schulz, Volkmar, and Cohen, 2002).

The top level of the model illustrates the three major categories of information that people with AS process erroneously: *information about others,* for example the thoughts, intensions and experiences of others; information about *the self,* such as understanding and regulating their own emotional experiences, *and nonsocial information,* which is related to more executive functions, such as, planning, shifting attention and central coherence (the ability to look at information within a wider context).

The second level describes how these processing deficits manifest on a day to day basis; for example, socially, and with every day skills required in daily living, e.g. task management and problems solving. Gaus suggests that struggles with social skills and self management could lead to individuals developing maladaptive negative schemas about the self. The third level demonstrates the social and practical repercussion of these difficulties, such as social rejection, ridicule, and stress in trying to cope with everyday tasks, all of which might easily lead to the development of negative schemas about the self and other people. The daily hassles and stressful events might also cultivate negative schemas about the self and the world in general. The model goes on to illustrate how poor social skills and social rejection can lead to inadequate social support which, when coinciding with chronic stress related to the constant struggles with daily tasks can lead to people with AS to become vulnerable to developing mental health difficulties such as anxiety and depression.

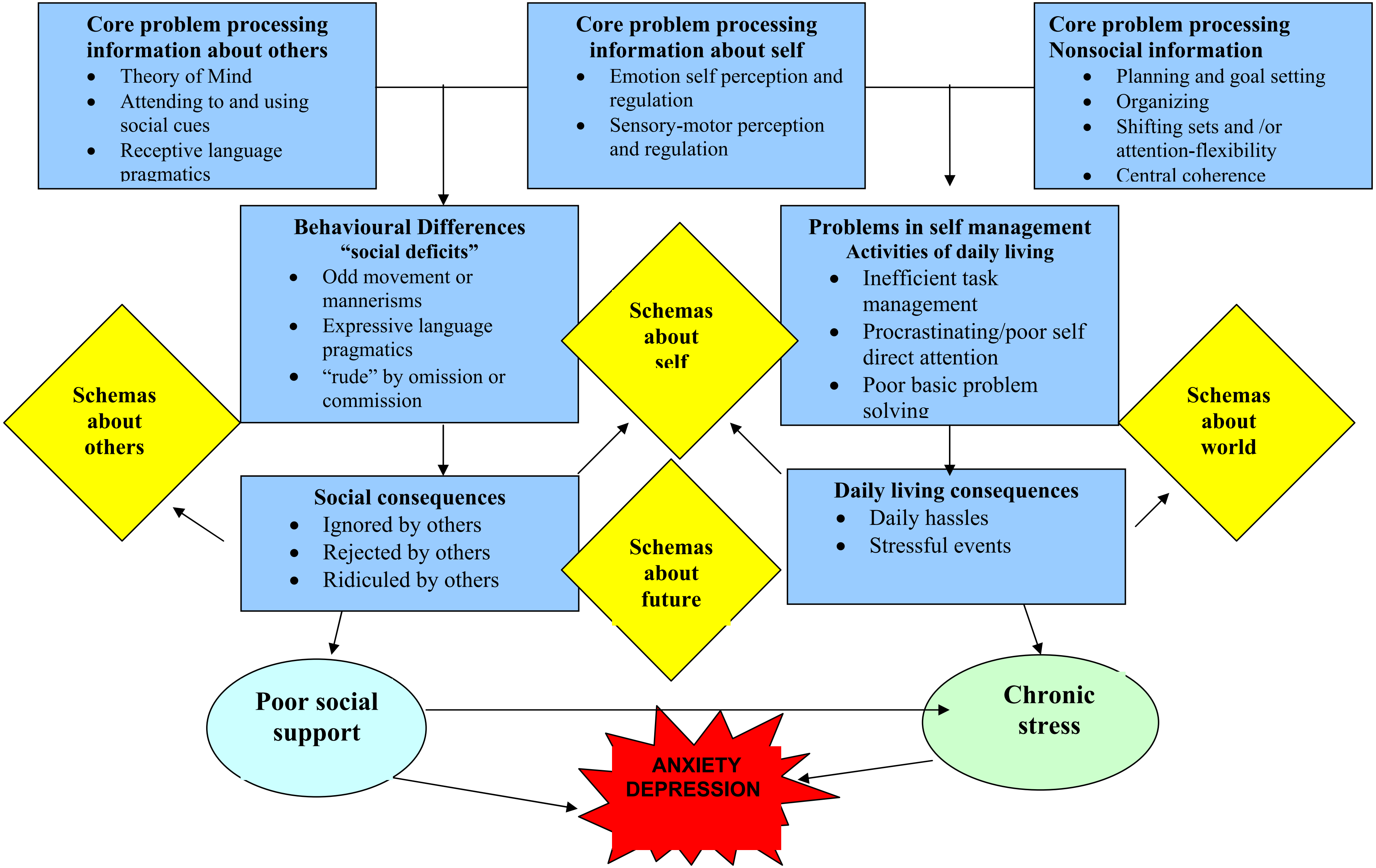

Fig 1. Core problems in AS and pathways to mental health problems. Adapted from Gaus, 2007

1.2 Cognitive Behaviour Therapy and Asperger's Syndrome

Cognitive Behavioural therapy (CBT) can be described as a group of approaches which is underpinned by the assumption that emotional distress and behaviour are based on cognitive distortions, such as dysfunctional thinking and incorrect assumptions. CBT is widely considered as a suitable (evidenced based) psychological treatment for mood disorders, such as anxiety and depression (NICE guidelines manual, 2007).

Hare (1997) and Attwood (2003) note that the rigid, negatively biased thinking patterns evident in people with AS are similar to those of individuals with anxiety and depression. Both are also of the view that perhaps meta cognitive impairments, such as cognitive inflexibility, executive function and problems within Theory of Mind can benefit from meta cognitive approaches such as CBT. A distinct paucity of research in this area is perhaps indicative of a common assumption influenced by research into Theory of Mind, that children and adults on the spectrum have difficulty in identifying emotions and cognitions both in themselves and other people (Baron-Cohen, 2001; Baron-Cohen, Leslie, and Frith, 1985). However, as reported in Chalfant et al (2004) recent findings have produced evidence to the contrary (e.g. Bauminger and Kasari, 1999; Dahlgren, Sandberg, and Hjelmquist, 2003) Furthermore, a study conducted by Chalfant et al found that children with HFA demonstrated the ability to identify thoughts that reflected their emotional states; a main requirement for CBT.

Strategies originally developed for children have been found to be effective with an AS population, such as social stories and comic strip conversations (Gray, 1998). Such techniques can be helpful in identifying thoughts, beliefs and intentions, correct erroneous assumptions or to explain the perspectives of others.

Attwood (2003), a leading authority in Asperger's syndrome, developed a metaphorical technique to facilitate the process of cognitive restructuring with children, using the concept of an emotional 'toolbox', with different types of tools to 'fix the feeling'. The aim of this strategy is to identify different types of 'tools' to fix the problems associated with difficult emotions such as anger, anxiety and sadness. For example, 'physical tools', one of which is represented by a picture of a hammer, can represent safe actions that release physical energy, while thinking tools, such as a screwdriver, symbolizes activities to test the reality and probability of feared outcomes. He also suggests incorporating the person's special interest where possible; for instance, the metaphor of the child as a scientist or astronomer exploring a new planet or continent.

So far, two reviews have been conducted within this area. Anderson and Morris (2004) review important components of cognitive behavioural therapy in relation to its use with adults and children who have Asperger's syndrome. They propose that subtle impairments in Theory of Mind and executive functioning poses challenges for such individuals in being able to tolerate a conventional therapeutic relationship, describe emotions and associated thoughts, and generate alternative solutions and beliefs. However, they conclude that through creative modifications, the use of CBT techniques with individuals with AS appear 'promising'. White (2003), attempted a brief review of the effects of CBT in children with autistic disorders, which included one randomized controlled trial, (Sofronoff and Attwood 2003), and two case studies, (Bauminger 2002; Reaven and Hepburn, 2003). He concluded that there was insufficient evidence to conclude whether CBT had any positive effect. Two of these studies are also reviewed here.

The purpose of this review

So far, there has not been a full systematic review of the efficacy of CBT for adults and children on the higher functioning end of the spectrum. Despite the small extent of the literature base in this area, a closer look at the effectiveness of CBT in alleviating psychological distress within this population is warranted at this time as mental health problems in this population pose significant problems. Consequently, the objective of this review is to establish whether research carried out to date provides sufficient evidence for the effectiveness of CBT within this population. The studies will be evaluated methodologically and recommendations for future practice and research will be made based on the evidence reviewed.

2. Method

2.1 Search Strategy

Computerized searches of databases were undertaken between September 2007 and January 2009. Data bases used were:

- OVID (CAB Abstracts, Econlit, EMBASE, MEDLINE, PsychINFO)
- Web of Knowledge
- National Autistic Society database

Combinations of the following words were used: Cognitive Behavioural Therapy, Cognitive Behavioural Intervention, CBT, Asperger's, AS, High Functioning Autism, HFA, Autistic Spectrum Disorder, ASD,

A search of abstracts was then conducted and any articles that involved the evaluation of cognitive behavioural therapy with adults or children with Aspergers syndrome or high functioning autism were selected.

2.2 Selection Criteria

When discussing application of cognitive behavioural therapy with people with learning disabilities, Dagnan and Chadwick (1998) proposes that there are two identifiable types of application of cognitive behavioural therapy:

- 'deficit orientated CBT' - This first type is concerned with teaching skills and maintaining on-task behaviour, and is largely derived from the self instructional literature. In terms of people on the autistic spectrum, a typical example would be the development of Theory of Mind skills. Social skills training would also come under a 'deficit model'.
- 'error-orientated CBT' – The second approach to CBT, has developed from psychotherapeutic methods and is concerned with emotional disturbance. Emotional and behavioural disturbance is thought to be the result of maladaptive cognitions. Consequently, this nature of this approach concentrates on making psychological changes in terms of addressing thinking errors, such as dysfunctional beliefs and perceptual bias.

The current review has selected studies that mainly involve the evaluation of the second form of application; error-orientated CBT, with an emphasis on cognitive content rather than cognitive process (Kendall, 1992). This is because the focus is on the effectiveness of CBT in alleviating psychological distress and emotional disturbance. Furthermore, this specific focus allows for a more in depth review. However, the majority of the studies have also incorporated aspects of deficit orientated CBT. Given the complex nature of the client group this combination approach is to be expected. Consequently, it was impossible to exclude all papers with any aspect of the first type of approach due to this tendency for overlap. However, papers included were selected on the basis that they reported predominantly on cognitive content type measures

Studies considered for inclusion were single case studies, case series and randomized and non randomized controlled trials from peer review journals published between 1997 and 2008.

2.3 Search Findings

A total of 32 papers were found of which eight met inclusion criteria. Those excluded were conceptual in nature, social skills orientated, or those which did not contain outcome data. In addition hand searches of references found three additional papers. The final selection comprised of seven single case studies and four randomized controlled trials (RCTs), the details of which are displayed in Table 1 and 2 respectively.

2.4 Framework for critiquing the literature

Each article was critiqued based on its research design, modifications to the approach and the assessment and outcome measures used to evaluate effectiveness.

To assist in the evaluation, the single case studies were subject to methodological evaluation based on The Single Case Experimental Design Scale (Tate, McDonald, Perdices, Togher, Schultz and Savage 2008). The author searched for a quality criteria checklist more suited for single cases but none were found. Consequently, the scale produced by Tate et al was adapted and used. It was identified that the issue of selection and quality of measures used is not included in the rating table however, this issue is covered in the text.

In terms of the RCTs, a ‘quality assurance criteria checklist’, devised and adapted from the review criteria recommended by the American Academy of Neurology Clinical Practice Guidelines (2004), was used. Scores for both checklists are presented in Table 3 and 4 respectively. Both checklists assessed aspects of the studies’ theoretical basis, design, measures, analysis and results. Each item on both lists was rated 0-2; a score of 0 indicated ‘*no evidence*’, ‘1’ indicated *partially or somewhat evident*, and a score of ‘2’ indicated ‘*definitely yes*’.

Table 1: Summary of selected studies: Single Case Reports

Single Case Designs: Adults						
Author (year) Origin	**Study Title**	**Design**	**Sample size and clinical group**	**Intervention details**	**Measures used (pre/post/follow up)**	**Findings**
Hare (1997) *UK*	The use of cognitive behavioural therapy with people with Asperger's Syndrome	Single case study	26 year old male with AS presenting with depression and self harm.	12 sessions of CBT. Sessions based on responses to weekly BDI and thought diaries. Strong cognitive component with behavioural tasks	i) BDI- (Beck, 1961) completed weekly. Follow up assessment at 6 and 8 months	No further occurrences of self harm. BDI scores decreased from 29 (severe) at pre treatment to 13 (minimal) at post treatment. Some increase in depression observed at 6 and 8 month follow up but not to pre treatment level.
Cardaciotto and Herbert (2004) *US*	CBT for social anxiety disorder in the context of AS: A single subject case	Single case study	23 year old male with AS and social anxiety and depression	14 weeks of individual CBT intervention based on a version developed by Heimberg and Becker (2002). Adapted for social phobia. Treatment focused on social skills, anxiety management and cognitive restructuring.	i) Social phobia and Anxiety Inventory (SPAI) (Turner et al ,1994) ii) Social Anxiety Scale (LSAS) (Liebowitz, 1987) iii) BDI-II (Beck et al, 1996) iV) Clinical Global Impression (National Institute of Mental Health, 1985)	BDI scores decreased from 23 (severe) to 11 (minimal) SPAI – post treatment scores fell near 50th percentile for non anxious controls and 40th percentile for non anxious controls at two month follow up. play. LSAS –Some decrease in avoidance. Fear rating did not decrease below pre treatment level. Improvement in social skills limited, assessed through role
Single Case Designs: Children						
Reaven and Hepburn (2003) *US*	Cognitive behavioural treatment of OCD in a child with Asperger's Syndrome	Single case study	7 year old female with AS and Obsessive Compulsive disorder	14 sessions. Content adapted from March and Mulle (1998) manual. Exposure/response prevention. Use of metaphors, visuals, cognitive statements and Social Stories.	Yale-Brown Obsessive Compulsive Scale (CY-BOCS), (Goodman et al, 1986)	After 14 weeks, 65% decrease in symptoms. Scores decreased from 23 at baseline to 8,post treatment. Qualitative reports indicate general improvements in daily functioning. Client reported improvement of symptoms using a visual scale and visual mapping tool.

Table 1 continued

Author/ year Origin	Study Title	Design	Sample size& clinical group	Intervention details	Measures used (pre/post/follow up)	Findings
Sze and Wood (2007) *US*	Cognitive Behvaioural Treatment of co morbid anxiety disorders and social difficulties in children with HFA	Single case study	11 year old female with HFA and anxiety (GAD, SAD, OCD) and social difficulties	Enhanced CBT manual consisting of Psycho-education, basic level cognitive restructuring and emotion recognition, in vivo exposure work and skills training.	i) Anxiety Disorders Interview Schedule (ADIS-c/p); (Silverman &Albano, 1996) Pre and post only.	Investigators reported that the child no longer met criteria for SAD, GAD and OCD also decrease in separation anxiety reported.
Sze and Wood (2008) *US*	Enhancing CBT for the treatment of Autistic Spectrum Disorders and concurrent anxiety.	Single case study	10 year old boy with AS, GAD and Social Phobia (SoP)	Basic level cognitive restructuring, hierarchical exposure work, use of visuals and cartooning. Also incorporated use of metaphors and special interests.	i) Anxiety disorder interview schedule (ADIS-c/p) (Silverman & Albano, 1996) ii) Clinical Global Improvement Scale(National Institute of Mental Health, 1985) iii) Multi dimensional Anxiety Scale (MASC) (March, 1998) IV)Child Behaviour Checklist (CBCL) (Achenbach, 1991) V)Vineland Adaptive Behaviour Scales (VABS) (Sparrow et al, 1984).	No longer met diagnostic criteria for GAD and SoP. Anxiety symptoms 'very much improved' on the Clinical Global Improvement Scale. Improvements in daily living skills as reported in VABS.
Lehmkuhl et al (2008) *US*	Exposure and response prevention for OCD in a 12 year old with Autism	Single case Study	12 year old male with HFA and OCD	CBT with exposure and response prevention. Treatment model adapted from March and Mulle (1998). 16 sessions.	i) Yale-Brown obsessive compulsive scale (CY-BOCS); (Goodman et al, 1986) ii)Child Obsessive Compulsive Impact Scale (COIS), (Piacentini et al, 2003) Pre and post.	Reduced scores on CY-BOCS. Post scores reported to be within 'normal limits'. COIS also within 'normal limits'.
Greig and Mackay (2005) *UK*	Asperger's Syndrome and Cognitive Behaviour Therapy: New applications for Educational Psychologists	Single case study	12 year old male with AS and anxiety and depression	'The Homunculi' (Latin meaning 'Little men'). A meta- cognitive, metaphorical visual aid. Uses the concept of different charactors who live inside different parts of the brain and who control thoughts and feelings. 15 sessions.	i) Trauma Symptom Checklist for Children (Briere, 1996)	Significant decrease in anxiety, depression and anger scores. Mean scores comparative with those of same age peers. Social competence outcomes did not show same level of improvement but comparative with same age AS peers.

Table 2: Summary of selected studies: Randomized controlled trials

Randomized Controlled Trials							
Author/ year Origin	**Study title**	**Design**	**Sample size and clinical group**	**Recruitment and assessment information**	**Intervention details**	**Outcome Measures used**	**Findings**
Sofronff and Attwood (2003) *Australia*	A Cognitive Behaviour Therapy Intervention for Anxiety in Children with Asperger's Syndrome	RCT Grp1- child only Grp2 – child and parent Grp3 – waiting list	65 Children (aged 10-12yrs) with AS. Adjunctive parent training.	Via local newspapers, radio, AS support network	6x 2 hr sessions -affect education, relaxation ,cognitive restructuring , coping strategies. Use of metaphors such as emotional 'tool box' concept Social stories and comic strip conversations.	Only three reported. All none standardized. i) Senario. assessing ability to generate strategies for anxiety (Attwood, 2002). ii)Parental self efficacy (Sofronoff et al 2002) iii) parent feedback.	Results suggested improvements in parent self efficacy and in child coping strategies in two intervention groups. Most improvements produced in child-parent group
Sofronoff, Attwood and Hinton (2005) *Australia*	A Randomized Control Trial of a CBT Intervention for Anxiety in Children with AS	RCT Grp1- child only Grp2 – child and parent Grp3 – waiting list	71 Children (aged 10-12yrs) with AS Adjunctive parent Training.	Via local newspapers, radio, AS support network	6x 2 hr sessions -affect education, relaxation, cognitive restructuring , coping strategies. Use of metaphors such as emotional 'tool box' concept Social stories and comic strip conversations	i) Senario –assessing ability to generate strategies for anxiety. i) Spence Child Anxiety Scale-parent. (Nauta et al, 2004) iii)Social worries questionnaire –parent –(Spence, 1995)	Results suggested reduced anxiety and improved coping in two intervention groups. Largest decrease in anxiety in child- parent group.

Table 2 continued

Author (year) Origin	Study title	Design	Sample size and clinical group	Recruitment and assessment information	Intervention details	Measures used (pre/post/follow up)	Findings
Sofronoff, Attwood and Hinton (2007) Australia	A Randomized Control Trial of a CBT intervention for Anger Management in children with AS.	RCT Grp 1-Intervention Grp2- waiting list	45 children (aged 10-14) with AS and their parents. Adjunctive parent involvement	Recruited from Brisbane via media release	6x 2 hr sessions Consisting of : affect education, relaxation, cognitive restructuring , coping strategies. Also incorporated use of metaphors such as emotional 'tool box' concept Social Stories and comic strip conversations. Parents in grp2 received same training.	i) Scenario – assessing ability to generate strategies to manage anger (Atwood, 2004) ii) Children's Inventory for Anger (Sofronoff, 2003). iii) Parent monitoring of anger episodes iV) parents' confidence in management. V) Qualitative feedback in questionnaire for parents and teachers.	Reduced frequency and severity of anger in intervention group, compared with WL group. Parents reported increase in confidence and ability to manage anger episodes in their child.
Chalfant, Rapee and Carroll (2007) Australia	Treating Anxiety disorders in children with HFASD: A controlled trial	RCT Gp1 – Intervention Grp2 – waiting list	47 children(aged 8-13) Diagnosis of AS/HFA Adjunctive parent involvement. .	Recruited through referrals from community health centres, MH profs, and parents after media releases in the autism association magazine	Family based CBT treatment. 9x 2hr sessions. 3xmonthly top up. CBT based programme consisting of affect education, simplified cognitive restructuring, relaxation and graded exposure,	i)ADIS-C/P ii) The revised Children's Manefest Anxiety Scale (Reynolds & Richmond; 1978) iii)Spence Children's Anxiety Scale – parent Iv)Child's Automatic Thought scale (Schniering & Rapee, 2002) V) Strengths and Difficulties Questionnaire – parent and teacher (Goodman, 1997)	71.4% of participants (20 out of 28) no longer fulfilled diagnostic criteria for anxiety disorder. This compared with 0 out of 19 in waiting list condition. Parents and teachers reported reduction in symptoms

3. Results: Single Case Studies

Table 3 Quality Assurance Rating of Single Case Experimental Designs (Tate, McDonald, Perdices, Togher, Schulz and Savage, 2008)

	Hare (1997)	Reaven and Hepburn (2003)	Cardaciotto and Herbert (2004)	Greig and Mackay (2005)	Sze and Wood (2007)	Sze and Wood (2008)	Lehmkuhl et al (2008)
Is there sufficient clinical history to allow for reader to judge applicability of treatment to another individual?	2	2	1	2	2	2	2
Is the problem adequately identified?	2	2	2	1	1	2	2
Does the study design allow for examination of cause and effect relationships to demonstrate treatment efficacy?	0	0	0	0	0	0	0
Has an adequate baseline measure been provided?	0	0	0	0	0	0	0
Was sufficient sampling of behaviour/target problem taken during treatment to differentiate treatment response form natural fluctuations?	2	0	2	0	0	0	0
Is there a raw data record to illustrate variability of target behaviour/problem?	2	0	2	0	0	0	0
Is there inter rater reliability?	0	0	2	0	2	2	0
Were independent assessors employed to reduce assessment bias?	0	0	2	0	2	2	0
Was statistical analysis used to analysis the results over the study phases?	0	0	0	0	0	0	0
Was the treatment replicated with other individuals to demonstrate treatment not limited to individual or setting?	0	0	0	0	0	1	0
Generalization demonstrated? Was the functional utility of the treatment extended beyond target behaviours or therapy environment into other areas of individual's life?	1	1	1	1	1	1	1
TOTAL	9	5	12	4	8	10	5

3. 1 Included studies

Of the seven single case studies, only two involved adults, one of whom presented with depression and self harm, (Hare, 1997), the other with social anxiety and depression, (Cardaciotto & Herbert, 2004). The remaining five studies involved children between the ages of 7-12 who presented with a range of anxiety disorders, (Greg & Mackay, 2005; Lehmkuhl et al, 2008; Reaven and Hepburn, 2003; Sze & Wood, 2007; Sze &Wood, 2008). A summary of these papers can be found in Table 1.

3.2. Adults

3.2.1 Design

Cognitive restructuring featured heavily in Hare's study, for example, eliciting evidence for and against negative thoughts and developing skills around finding accurate sources of information. Direct challenging of thoughts was avoided. Cardaciotto and Herbert also reported cognitive restructuring strategies as well as in vivo exposure, which were modified through simplified step by step explanations.

A strength of both studies is the presentation of multiple data points illustrating regular scores across the treatment period. This indicated differentiation between treatment response and natural fluctuation of symptoms. However, insufficient assessment points at baseline and follow up, a common problem in case studies, means that an accurate picture of the presentation of the problem had not been established. This makes a cause and effect relationship difficult to ascertain. A strength of Cardaciotto et al was the use of an independent assessor which served to minimize investigator bias. This was overlooked in Hare's study, although the involvement of the client's keyworker as co-therapist throughout treatment provided a degree of external objectivity in terms of client self reporting and also helped facilitate generalisation of skills across settings.

3.2.2 Measures

Cardaciotto and Herbert et al used a broad selection of assessment instruments and methods which tapped into different dimensions of anxiety, and included formal diagnostic tools as well as standardized self report questionnaires and role plays. In contrast, Hare mainly relied on one self report measure, although the BDI is renowned for its reliability and validity. Treatment gains were also assessed through achievement of therapy goals although these were only reported anecdotally (e.g reduction of self harming behaviour and solitary drinking)

3.2.3 Results

No formal statistics were conducted in either study, which implies that a reliable change cannot be confirmed. Although graphical presentation of scores in both studies allowed for visual inspection of changes over time

Hare reported BDI scores (see Table 1), which suggested a decrease from 'severe depression' to 'minimal depression' at post treatment. Six month and eight month follow up assessments indicated elevations in scores, although this was not to pre treatment levels. There were no further reported incidents of self harming behaviour or solitary drinking, which suggested an ability to generalize skills across settings.

Similarly, Cardaciotto and Herbert reported decreases in levels of anxiety and depression. At three month follow up there was a slight elevation in anxiety, which was explained through the client initiating more social contact. However, social performance assessments in the form of role play did not yield the same success. Although symptoms of anxiety and depression improved over the course of treatment, it is unclear whether these were clinically relevant or what aspects of the intervention were responsible.

Although follow up assessments were introduced in both studies, a single points of measurement means that it is not possible to establish a stable picture of clinical presentation.

3.3. Children

3.3.1 Design

Modifications reported by all studies were simplification of cognitive restructuring techniques, increased use of visual material such as cartoon strips and thought bubbles to aid cognitive restructuring, use of metaphors, incorporating special interests and narrative techniques, (see Table 1 for more details).

As illustrated in Table 3, all studies scored 0 in relation to sufficient sampling of target behaviours. The author recognizes that this is a general design weakness of single cases as opposed to experimental designs. Only two of the five studies collected data at four separate points, pre, mid, post and follow up (Lehmkuhl et al 2008 and Sze and Wood 2008). The remaining three reported pre and post outcome data only. A further weakness in four of the studies is the possibility of observer bias, an exception being the two studies by Sze and Wood who used independent assessors, blind to treatment aims. They also incorporated inter-reliability checks in both of their studies as did Cardaciotto and Herbert.

The majority of studies attempted to generalize skills learned across settings, which were facilitated through parental involvement. Although, formal assessment of this was only undertaken by Sze and Wood 2007, 2008 and Reavon and Hepburn. Greig and MacKay had a specific focus on making improvements within the classroom. However, formal measures were not undertaken with teachers. Lehmkuhl and colleagues provided information to teachers of skills taught in the session in order to facilitate generalisation to the classroom environment. Although, they too did not formerly assess the target problem within the classroom setting.

Two of the five studies comprised of several treatment components that targeted several different problems, (Sze and Wood, 2007, 2008). Consequently, it is not possible to ascertain which aspect of therapy was effective for which problem.

3.3.2 Measures

All studies used empirically sound and relevant measures and incorporated formal assessment of the target problem. Sze and Wood (2008), were particularly strong in this area. They used a multi model method which involved both formal and self report measures of different aspects of anxiety. They also assessed generalisability to the home setting and collateral improvements in general areas of functioning. A limitation of Greig and MacKay was their dependence on a single self report measure used only with the child, of which only three scales were used. The use of multiple data sources, such as parents and teachers, may have increased the robustness of the findings reported.

3.3.3 Results

All studies reported treatment gains and general improvements in symptoms as detailed in Table 1. However, statistical analysis was not undertaken by any of the studies. The majority presented before and after scores with the exception of Sze and Wood, 2007 who merely report that the child had met diagnostic criteria for three types of anxiety at baseline and was no longer the case at post treatment.

Grieg and MacKay compared emotional state outcomes with mean scores derived from a normative population (non AS). Results indicated that at post treatment, the client's anxiety, anger and stress scores were at approximately the mean value for his age. Scores for social competence were equivalent with mean scores derived from AS sample, although they were much lower when compared with a normative non AS sample. Confidence in the findings produced by Greig and MacKay are weakened by lack of an independent assessor, particularly in the light of the personal role of the assessor in the development and implementation of the intervention.

A crucial factor which limits the robustness of the findings reported by Reaven and Hepburn is the possible confounding effects of medication, (Sertraline for OCD symptoms), which was prescribed three months into treatment. Similarly, Sze and Wood (2007), note that their client was receiving 'occasional' school counselling parallel to the intervention. Confounding factors were not controlled for in either study which makes it impossible to ascertain whether improvements can be attributed to psychological intervention, and if so how much.

Results reported by Sze and Wood (2007), are hindered through absence of any clear description of results such as assessment scores, raw data, or visual displays of results. This is particularly surprising given the use of a robust and comprehensive anxiety measure. Results displayed in their follow up study (2008), were more detailed. T-scores and standard deviations allowed for comprehensible comparisons between pre, post and follow up measures. School adjustment outcomes, which were based on informal teacher reports, also indicated an improvement; although, the reporting and method of data collection of these results were unclear.

3.4 Discussion of Single Case studies

The quality assurance checklist indicates that the strongest study was Cardaciotto and Herbert (2004). Particular strengths were multiple assessments points across treatment period and use of independent assessors and inter-rater reliability. The lowest scoring studies were Lehmkuhl et al (2008) and Reaven and Hepburn (2004). Both of which consisted of a number of methodological weaknesses that posed a threat to internal and external validity of the findings produced.

Limitations of the child cases include lack of controlling of confounding variables and inadequate data collection points particularly at baseline, which hinders confidence in attributing improvements to treatment efficacy. Furthermore, absence of any statistical analysis or presentation of means and standard deviations indicate that reliable change is difficult to conclude.

Attempts to generalize skills taught in the clinic environment to other settings was evident in the majority of the studies. In the case of the child studies, this was facilitated through involvement of parents, and to some extent, teachers; although, formal independent teacher ratings would have provided a more objective measure of generalization. Nevertheless, this collaborative process can help to reduce pressure on families and teachers, and encourages consistency and generalization of skills taught across settings.

Generalisability across populations is a well known limitation across all single case reports. In the studies under review, the extent to which characteristics of the children, their environment and input by family and school contributed to the outcome is unclear. Although all studies provided a clear description of clinical presentation, there was a paucity of description concerning individual characteristics such as severity of ASD as well as linguistic and cognitive abilities.

It is acknowledged that single case studies provide poor quality evidence for the effectiveness of an intervention in that they lack a control and systematic manipulation of a target variable. Furthermore, insufficient data points means it is not possible to establish the nature of the target problem prior to treatment and whether any fluctuations reflect improvements related to the intervention. Although it is acknowledged by the author of this review that the studies don’t claim to be single case experimental designs, these elements described in the quality assurance table provide useful guidelines for higher quality research.

4. Results: Randomized Controlled Trials

Table 4 Quality Assurance Rating Table for Randomised Controlled Designs Adapted from American Academy of Neurology Clinical Practice Guidelines (2004)

Rational and Design	Sofronoff and Attwood (2003)	Sofronoff, Attwood and Hinton (2005)	Sofronoff, Atwood and Honton (2007)	Chalfant, Rape and Carroll (2006)
Was there a theoretical/conceptual basis for the study?	2	2	2	2
Were aims and objectives clearly presented?	2	2	2	2
Was the methodology described in a clear manner that would allow replication?	2	2	2	2
Was the study longitudinal?	0	0	0	0
If so, is it over a period longer than a year?	0	0	0	0
Did the study use a comparison group?	2	2	2	2
If so, were initial group difference accounted for?	unknown	2	1	2
Were participants systematically selected (representative of the population)	1	1	1	1
Sub-total	9	11	10	11
Sample and Measures				
Was the study sample homogenous in type and severity of target problem?	unknown	0	1	0
Were reliable and valid measures used to measure variables, e.g. anxiety	0	1	1	2
Were variables used to measure outcome appropriate in relation to aim of the study aim?	1	2	2	2
Sub-total	1	4	4	4
Results				
Were confounding variables controlled for?	0	unknown	1	1
Were suitable statistical analysis employed?	Unknown	1	1	1
Was the sample size enough to detect meaningful effect?	1	1	1	1
Are the results generalisable across population?	Unknown	1	1	1
Are the results generalisable across settings?	1	1	1	2
Subtotal	2	5	6	6
T OTAL	12	20	20	22

4.1 Included studies

All of the RCTs involved child participants with an age range of between 8-14 years. The number of participants across the trials varied between 45 and 71. Three of studies evaluated a CBT programme in group therapy format, which aimed to address anxiety disorders (Chalfant, Rapee & Carroll, 2006; Sofronoff, Attwood and Hinton, 2003; 2005), whilst the fourth evaluated the effectiveness of a CBT anger management group. (Sofronoff & Attwood, 2007).

4.2 Design

All four studies scored highly in terms of sufficient detailing of procedure and modifications to enable replication. Details of the interventions are provided in Table 2.

Use of a waiting list control group along side an intervention group was employed in all four studies. In addition, Sofronoff et al, 2003 and 2005 introduced a third condition which involved training parents as ‘co therapists’ in order to assist with generalisation to the home setting.

In comparison to the three studies produced by Sofronoff et al, Chalfant et al provided thorough details of inclusion and exclusion criteria. However, children excluded from the study included those with physical disabilities, Conduct Disorder and Oppositional Defiant Disorder. Given the complex presentation associated with this population, it is arguable that this may undermine their representativeness of children seen in a clinic setting.

Participant demographics and selection criteria was absent in Sofronoff (2003), which made it impossible to ascertain generalizability, as well as the extent of any selection bias, or whether there were any prior confounding differences between groups. An additional concern is the authors’ neglect to mention details of any drop outs, so it was unclear whether an intention to treat analysis had been conducted. This study also failed to report recruitment source. On this latter point, Chalfant et al adopted a broader recruitment process, taking referrals from both medical professionals in clinics and parents in the community accessed via the media and support groups. This is in contrast to Sofronoff et al, (2005; 2007), who relied solely on media sources, which may hinder confidence in their representativeness of the typical clinical encounter.

Information regarding the long term effects of the interventions was only available in the three Sofronoff studies at six weeks post treatment. Chalfant et al reported intentions to collate information of long term benefits at 6, 12 and 18 months, which will provide a more reliable indicator of stability of efficacy over time.

4.3 Sample and Measures

Given the diverse range of anxieties experienced by the children in the groups, together with the heterogeneous nature of the population, it is fair to say that the groups in the three anxiety studies may not be homogenous in nature.

The highest score in relation to use of measures were given to Chalfant et al who used a diverse range of standardized measures with different sources. They were also the only researchers who employed formal diagnostic procedures to clarify the severity of the target problem and to ascertain whether this warranted a diagnosis beyond autism-related difficulties. Further confirmation was obtained both by standardized parent and child measures of anxiety. This stands in contrast to all three of the Sofronoff studies where this information was solely reliant on parent report measures, consequently, potentially open to bias if the response of parents were influenced by their desire for inclusion.

Sofronoff et al (2003) were rated the lowest in terms of outcome measures. They report that ‘several’ measures were used, but only three were reported. All or which were of unknown validity and reliability. This is problematic as it is unclear whether the positive results produced reflected genuine clinically important changes. Improvements in choice of measures were made in their follow up studies (2005, 2007).

4.4 Results

All four studies reported positive treatment effects (detailed in Table 1), although the robustness of the findings vary. Sofronoff et al (2003, 2005) reported that the most noticeable improvements were in the child-parent group. A main weakness of all three of the Sofronoff studies is that data largely depended on parent reports who may have felt pressured to indicate improvements. This was compounded by the lack of independent assessors during assessment interviews.

Sofronoff et al's first study (2003) did not provide details of any statistical analysis but merely reported P values. Consequently, the appropriateness of the statistical test used for the relatively small sample size (not homogenous in nature), is unknown. Presentation of means and standard deviations are also missing, which would have informed the reader as to whether changes were large enough to be clinically meaningful. Furthermore, it was not made explicit whether significant levels were adjusted to allow for multiple testing, which could increase the likelihood that any significant difference between groups being due to chance rather than genuine clinically important changes, (this was also the case in their 2005 study).

Although the above concerns were not evident in Chalfant et al or Sofronoff and Attwood (2007), the reporting of effect sizes or confidence intervals would have increased confidence in results being clinically meaningful.

In Sofronoff and Attwood (2007), means and standard deviations showed that only two subtests out of four of the anger measure showed significant effects and although an objective source of data on behavioural changes were provided by teachers, they were aware of the study which may have influenced responses.

Assessment of generalization to home and school settings was more adequately assessed by Chalfant and colleagues. Results provided details of actual probability values and means which indicated extensive improvements in levels of anxiety. However, some of the children were undertaking adaptive behaviour analysis training adjunctive to the study which may have confounded results. Other limitations were lack of independent evaluators blind to treatment assignment and lack of assessment of treatment fidelity. Nevertheless, a consistent pattern of results indicative of treatment gains across several information sources seem to add confidence to the results.

All studies had adequate but relatively small sample sizes according to standards proposed by Chamberless and Hollon (1998), who suggest 25-30 per group. This may limit generalisability and possibly call into question the use of parametric tests used in three of the studies.

A strength in all four studies is the adjunctive parent training which aimed to help the children generalize strategies across settings. Although all three of the Sofronoff and Attwood studies appeared to have a strong element of simplified cognitive restructuring, it was unclear how much this served as a mechanism of change alongside the behavioural strategies, whereas Chalfant et al incorporated a measure that aimed to assess cognitive shifting.

4.5 Discussion of Randomised Control Trials

Taken together, all four studies suggest some benefit in using an adapted CBT approach with children with high functioning ASD. However, there are a number of methodological limitations which have been discussed above.

The strongest evidence appears to be provided by Chalfant et al who scored the highest on the quality assurance rating table. Particular strengths were robust and thorough assessment procedures, a range of recruitment sources and clear sample description. However, a significant limitation across all studies is their lack of independent assessors and relatively small sample size. The homogeneity of participants is also questionable given the idiosyncratic nature of autism and the diverse range of anxiety disorders featured in the sample. However, demographic details, such as IQ were helpfully provided, as were the nature of the anxiety disorders; an exception being Sofronoff and Attwood (2003).

Parents reported positive treatment gains in all four studies. This supports previous findings that parental involvement in treatment for this population is beneficial (Keller and Tutin, 1995). However, self reports limit the robustness of this finding. Furthermore, it could be argued that benefits may be partly or wholly due to social gains of interacting with other parents in a similar position to themselves.

Chamberless et al raise the point that a particular intervention may fail to produce effective changes due to poor implementation rather than due to lack of efficacy per se.

A concern in all three of the Sofronoff et al studies is that intervention was implemented by postgraduate psychology students who had attended a one day training workshop. Although they state that 25% of therapy sessions were assessed by independent raters, this only amounts to 1.5 sessions. Assessment of treatment fidelity was not assessed by Chalfant et al. Both qualitative and quantitative reviews around treatment efficacy have consistently suggested that more robust findings are likely to involve assessment of treatment quality and fidelity by independent knowledgeable experts (Chamberless et al 1998).

Independent assessment to rate adherence to the CBT model is lacking in all four of the studies. Chalfant reported that the cognitive component of the child intervention was very much simplified, a necessity given the age group of the children Although, outcome measures used, such as the Child's Automatic Thought Scale (CATS) indicated significant levels of cognitive shifts amongst the children and a reduction in internalizing anxious thoughts. The effectiveness of any specific cognitive restructuring components involved in the Sofronoff et al studies is unclear.

The above studies go some way to exploring the appropriateness of using a modified group CBT approach for children within the high functioning range of the autistic spectrum, particularly in relation to anxiety management. However, three studies were from the same team which may have biased results. Together with methodological short comings, this prevents any confident conclusions from being drawn.

5. Overall Discussion

The research studies reviewed offer some evidence that implementation of CBT interventions with individuals on the high functioning end of the autistic spectrum can help improve psychological wellbeing. However, as evident in both quality assurance tables, few studies adhere to rigorous research standards, consequently reducing confidence in results. Furthermore, seven of the studies reviewed were single case studies. Although this type of study can offer rich details and inform of specifically tailored intervention and outcome, they are generally considered unreliable in providing empirical evidence.

Several modifications were made to the theoretical framework of CBT across all of the studies reviewed. These included incorporation of special interests and metaphors, clear structure and goals, increased use of visual material, and visual monitoring systems.

In order to meet individual needs and abilities, some of the studies reported simplified cognitive techniques and an emphasis placed in behavioural strategies, such as graded exposure and response prevention. Behavioural components of some of the studies may have also been strengthened through parental involvement by parents ignoring maladaptive behaviours and reinforcing adaptive behaviours. Subsequently, the extent to which some studies adhered to a CBT framework is questionable, particularly where details of procedures are distinctly lacking (e.g. Cardaciotto and Herbert, 2004). However, it is acknowledged by the author that gauging an appropriate balance between cognitive and behavioural strategies can be challenging for clinicians working with children. This would be particularly the case with children with ASD.

CBT indicates that changes in cognitive processes need to take place before reduction in the target problem. Sturmey (2005) argues that within learning disability research, many investigators describe their approaches as CBT when main procedures are actually behavioural, such as relaxation. He goes on to argue that a common error is mistaking techniques such as verbal reattribution, or respondent extinction for cognitive therapy as they involve verbal behaviour. Similarly, some of the studies in the current review report ‘Cognitive restructuring’ strategies, which were largely verbal reattribution techniques, such as, rehearsal of coping or neutralizing statements (e.g. Reaven & Hepburn; Lehmicult et al,). However, it could be argued that this is verbal behaviour that is being taught and reinforced through rewards, and merely replaces one behaviour with another.

Sturmey (2005), differentiates between such verbal reattribution techniques and cognitive therapy. He states that the former is an operant conditioning process where the target verbal behaviour is increased following a positive consequence, as opposed to cognitive therapy where a non-observable construct such as negative expectancy, is measured indirectly through the client’s verbalizations. A therapeutic procedure such as looking for evidence is then used to change this unobservable construct.

In discussing CBT with children, Stallard (2005), reports that direct focus upon cognitions is often limited. The ability of the child to engage in cognitive restructuring needs to be considers, particularly with young children and those with ASD. This then raises the question of how much of a focus on cognitive techniques should there be before an intervention can be said to be CBT. However, Stallard argues that cognitive change can occur indirectly through behavioural techniques such as exposure and response prevention and that the powerful role of behavioural techniques within CBT can, in some instance, be the main mechanism for change (Quakley et al, 2004).

Three of the RCT studies reviewed here assessed treatment fidelity to a CBT treatment manual. Future research into the efficacy of CBT for this client group should also incorporate measures for the adherence to a cognitive behavioural framework such as Cognitive Therapy Scale (Young and Beck, 1980, 1988). This scale was developed to measure therapist competence in CBT. A revised UK version was developed by Blackburn et al (2001). The scale consists of three key sections; general intervention procedure, interpersonal effectiveness and specific cognitive behavioural techniques. This latter section specifically measures implementation of use of guided discovery, case conceptualization, focus on key cognitions, application of cognitive techniques, application of behavioural techniques and homework.

Haddock et al (2001), developed a revised version to assess the competence of delivering CBT to individuals with psychosis (CTS-Psy). Given that some similar issues need to be considered when working with individuals with AS, perhaps future research could investigate how this scale could be adapted to measure cognitive skills with this client group.

Two studies in which cognitive restructuring techniques are evident are Hare (1997) and Greig and MacKay (2004). The latter describes specific techniques such as identifying unhelpful and erroneous thoughts, linking them to negative emotions and behaviours and looking for evidence and facts for and against such thoughts. The child's intellectual functioning was within the 'high average' range which would be important when considering generalisability to children and adults with a lower IQ. However, Hare's client was reportedly functioning within a 'low average' range and although procedures were simplified, an ability to engage in restructuring technique was demonstrated.

Regarding the RCTs, there was a diverse range of intellectual functioning which appeared to range from 'low average' to 'superior'. This would suggest diverse needs of group members not just in terms of IQ but in severity of ASD symptoms. Selecting a more homogenous group would make it easier to design a programme more congruent to all service users cognitive and intellectual abilities.

The selection of measures used in the studies tended not to identify specific mechanism of change but instead captured general changes in terms of coping skills and symptom severity (an obvious priority when assessing treatment efficacy). An exception is Chalfant et al who additionally used a specific tool to measure internalising thoughts related to anxiety. Results suggest that children in the study were not only able to identify thoughts but were also able to demonstrate cognitive shifting. Future research could aim to conduct a detailed analysis to identify a number of measures in which one can distinguish the mechanism of change in psychological wellbeing and whether this has been achieved through cognitive processes or some other mediating factors.

A further issue is the use of clinical assessments developed and standardized on a non autistic population and whether they are appropriate to use with the autistic population.

It is unclear as to whether knowledge and theories of psychopathology in the non autistic population can similarly be applied to people with AS, given their neurological and information processing deficits (Hare,1997).

In discussing suitability of CBT for the general population, Safran et al (1993) propose nine selection criteria including cognitive factors such as ability to process automatic thoughts, differentiate emotions and understand how they relate to cognitions and behavioural responses. Dagnan and Chadwick (1997; 2000), explored whether people with intellectual disabilities have the cognitive skills required to undertake cognitive behavioural therapy, such as the ability to recognize emotions, link events and emotions and recognize cognitive mediation. They concluded that some people with a learning disability have the capacity to understand and engage in a simple cognitive intervention. A valuable area to explore would be replication of this research with non learning disabled individuals with autism. Finally, it might also be beneficial, (before developing further treatment manuals) to go back to the drawing board and qualitatively explore the experience of anxiety and change in individuals with AS, and their actual experiences of CBT interventions.

6. Conclusions

The studies reviewed report that individuals with AS/HFA can benefit from CBT techniques in the reduction of symptoms related to mental health difficulties, although it is unclear as to the extent some of the techniques used adhered to a CBT framework. Due to the paucity of research available, particularly for adults, and methodological limitations, conclusions drawn must be tentative. Replication of such studies is critical, preferably by independent investigatory teams, which can provide some protection against investigator bias and findings that prove unique to a particular setting or group of therapists. While guidelines for CBT exist for the general population, it would be helpful to have them developed for this particular group of people.

It is important for therapists to be familiar with the common characteristics of ASD as well as the idiosyncratic profile of clients before considering their appropriateness for CBT and appropriate modifications. Furthermore, it may be helpful to assess the cognitive capacity of individuals in terms of their ability to engage in simplified cognitive demands of CBT, such as the ability to access thoughts and make links between cognitions, affect and behaviour (e.g Dagnan and Chadwick, 1997; 2000).

7. Recommendations

The National Institute of Clinical Excellence (NICE Guidelines Manual, 2007) have developed a classification system which indicates the level of evidence which contributes to the knowledge base: Class 1 (Randomised controlled trials), Class 2 (case-control or cohort studies) and Class 3 (case studies, case series or single case studies). Given that the studies reviewed here consist off seven Class 3 studies and only four class 1 studies there is insufficient evidence upon which to make any more than tentative clinical recommendations. Nevertheless a number of practice options (Cicerone et al, 2000), can be proposed, each of which is presented in the context of NICE levels of evidence gathered so far:

- Based on Class 1 and Class 3 studies: There may be difficulty in translating visual thoughts, (e.g in relation to anxieties or emotions) into words. Visual techniques such as diaries, monitoring charts, drawing and cartooning may be useful. .
- Based on Class 1 studies: Where possible, there should also be creative incorporation of special interests to facilitate modifying beliefs and maintaining engagement. Techniques such as social stories (Grey, 1993), cartooning and metaphors may also facilitate cognitive restructuring. There may also need to be a greater emphasis on affective education.
- Based on Class 3 studies, a more directive approach may be required at times rather than focusing on a collaborative therapeutic relationship. Therapy goals need to be broken down into manageable chunks and a clear explanation given regarding what realistically can and cannot be achieved.
- Based on Class 1 and 3 studies: Be direct, factual and explicit. Accommodate the client's desire to stick to facts. Make lists and rules.
- Based on Class 1 and Class 3 studies: Use of specific measures or visual monitoring system (e.g feelings thermometer), to be used regularly to illustrate change and

progress. Specific responses to items of the measures may be useful in guiding session content and helping client to notice change and progress.

- Based on Class 1 and Class 3 studies: In the case of children, involvement of parents and teachers as coaches can facilitate generalization and maintenance of skills across settings.

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First hand accounts of adults with Asperger's syndrome: An exploration into their experiences of being parented during childhood and adolescence.

by

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Abstract

Background

This study retrospectively explores the experiences of individuals with Asperger's syndrome (AS) of being parented during childhood and adolescence. Although there is extensive research examining experiences of parents in bringing up a child with an autistic spectrum disorder (ASD), there is a paucity of research from the perspective of individuals themselves, particularly those with AS, a form of high functioning autism.

Method

Semi structured interviews were conducted with seven adults. Interview transcripts were analysed using Interpretative Phenomenological Analysis.

Results

Four key themes emerged from the analysis: feeling nurtured and supported, feeling restricted/held back, a sense of loss and appreciation of discipline. Findings illustrate the importance of early detection / diagnosis as it appears to facilitate enhanced understanding and support from parents.

Conclusion

The relevance of the findings is discussed in relation to other research. It is important that professionals focus interventions to support parents in meeting the needs of children and young people with AS in order to facilitate a secure sense of self and psychological well- being in their child.

Key words: Phenomenological analysis, Asperger's syndrome, childhood, adolescence, parenting

Introduction

Aspergers Syndrome (AS) is a form of Pervasive Developmental Disorder (PDD) commonly considered equivalent to High Functioning Autism (HFA) (Gilchrist et al, 2001; Mayes and Calhoun 2001).

According to Conners & Stalker (2007), research relating to children with complex needs or disabilities tends to focus on the experiences of parents rather than those of the individuals themselves. Several studies focusing on parent wellbeing report increased rates of anxiety and depression in parents of children with ASD in comparison with parents of children who have other disorders (e.g. Bristol 1984).

Carter et al (2007) reported that although the etiology of ASD is thought to be partially neurobiological in nature, variations in parenting behaviours appear to influence the subsequent development of children with ASD. For example, they observed that the degree to which a mother offers a positive, encouraging environment in which the child can explore, and efforts to stimulate verbal and non verbal development were associated with the child's language development.

In line with this, Kuhn and Carter (2006), investigated maternal self efficacy and cognitions and reported that maternal agency (the extent to which a mother assumes an active role in the child's development), was positively correlated with maternal self efficacy, whereas maternal guilt, depression and parenting stress were negatively correlated with maternal self efficacy. Furthermore, mothers who had greater knowledge around autism were found to be more active in promoting the development of their child. Such findings highlight the importance of early detection and provision of support and education for families around the nature of autism and means of maximizing the child's social and communication abilities.

Increased stress levels for the mother and feelings of maternal guilt in relation to the child's diagnosis, together with the behavioural, interaction and communication characteristics of the autistic child may negatively affect the mother –child attachment process [reciprocal emotional bond with a caregiver over the course of infancy (Ainsworth, Blehar, Waters, and Wall, 1978;Bowlby, 1969] Howe, 2005). Marvin and

Pianta (1996), found that parents of children with disabilities who had not resolved their feelings associated with the diagnosis find it harder to be attuned and responsive to the child's cues, which in turn was associated with child attachment status (Stams et al , 2002). However, it has been reported that children with HFA are capable of developing secure attachments (Rutgers, Bakermans-Kranenburg et al 2004), a finding not demonstrated in autistic children with cognitive developmental delays. Dissanayake and Sigman (2001), suggested that this was due to impairment in emotional understanding and responsiveness being compensated by cognitive strategies utilized by higher functioning individuals.

It has been widely reported that close and supportive family relationships can act as a buffer against stress in children, lowering the likelihood of developing anxiety or depression (Bollmer, Milich, Harris and Maras, 2005; Bukowski, Hoza and Boivin, 1994; Hay, Payne and Chadwick, 2004), and that difficult family relationships can add to stress and adjustment problems (Cohen and Willis, 1985). Given that successful family interactions require socio-emotional skills (reported to be limited in children with ASD including AS/HFA), it is plausible that family interactions may have different degrees of impact on children on the autistic spectrum in comparison with other groups. Difficulties typically associated with low and high functioning autism such as understanding and expressing emotion, perspective taking, sensory sensitivity, and rigidity in cognitive processes could hinder the child's engagement in rewarding and supportive family relations, as well as their capacity to cope with negative family events or interactions (Kelly et al, 2008). Additionally, there may be problems relating to understanding and expressing affection (Bauminger, Shulman and Agam, 2003).

Kelly et al (2008), tested a multivariate model of family and peer relationships to explore to what degree quality of family and peer relationships and ASD symptomotolgy were related. Findings indicated that anxiety and depression and ASD symptomotology were significantly related and family conflict was predictive of ASD symptomotology.

An additional consideration is the possibility of one or more parent also being on the spectrum given that autism and AS has been suggested by some as having a genetic basis (Rutter, 2000). Certain characteristics associated with AS/HFA such as egocentrism and deficiency in compassion, empathy and reciprocity may mean that the parent might not be able to recognize and respond to the child's needs and put them before their own (Wall, 2003), which Gilberg, (1998), states may have repercussions including behavioural and psychological problems for the child.

Qualitative Research in HFA/AS

There is a distinct lack of research which seeks out the perspectives of individuals with autism. Williams (1996), stated that research into autism needs to hear 'the autistic voice'. This still remains very much applicable, although there has been a small amount of research which provides readers with an insider's view of the personal and social experiences of people with AS, e.g. Walker- Sperry (1998); Portway and Johnson (2003) and Carrington and Graham (2001). However, to date, there are only two published studies which uses Interpretative Phenomemological Analysis (IPA) to explore personal meanings of individuals with AS/HFA. Huws & Jones (2008) who explored the perceptions of young people with autism around diagnosis disclosure and Williams (2004), who explored experiences of theory of mind using ten published autobiographical accounts written by individuals diagnosed with either HFA or AS.

Study Aims

This study aims to explore the childhood experiences of individuals with AS specifically focusing on their views of how they were parented. Initially, the study had a wider focus on family life and relationships, which is reflected in some of the questions in the interview schedule. However, due to the richness of the data generated in relation to experiences specifically with parents, it was decided to narrow the focus for the current paper to concentrate on this issue more specifically.

Accounts are based on the retrospective recollections of adults as it was considered that they may have had the opportunity to examine their childhood experiences from an adult perspective, over longer periods of time, and in the light of their diagnosis.

Through adopting an IPA approach I aimed to gain insight into some of the challenges, as well as the positive experiences encountered in childhood in terms of being parented and the meanings these experiences hold for them. This approach does not lend itself to generalisability. However it is hoped that this can help to identify what participants found helpful and unhelpful and how they would have liked things to have been different.

Method

A Qualitative perspective

The current study adopts an Interpretative Phenomenological Analysis approach (IPA: Smith,2003; Smith, Jarman, & Osborn, 1999). This specific method was considered appropriate as it focuses on trying to understand the way participants make sense of certain experiences and of the personal meaning they attribute to such events. I am interested in the way that individuals with AS process information, which influenced my selection of this approach. Although IPA shares many features with the Grounded Theory approach, a more established qualitative method, IPA is concerned with individual experiences and gaining access to individuals' psychological world. Grounded Theory, on the other hand, was developed to study social processes and is therefore thought to be better suited to address sociological research questions (Willig, 2001: p68).

I have attempted to demonstrate that the findings are firmly grounded in the data. throughout the analysis process, I have checked the analysis and emerging themes with my research supervisor and other trainees in an attempt to search for any irregularities in the analysis process. I have also endeavored to describe the method in sufficient detail to enable replication. In doing so, it is hoped that the experiences of participants and their personal meanings are sufficiently portrayed and plausible to the reader.

Sampling

Nine participants were recruited and interviewed which is consistent with the recommended sample size for IPA (Smith 2003). All were male aged between 20 and 57. It was hoped a mixed gender sample would be recruited but this was not possible. Participation was on a purely voluntary basis and participants were paid £10 for their time. Ethical approval was obtained from South Staffordshire Local Research Ethics Committee on 7th April 2008 (see Appendix 2).

Recording of one interview was not successful due to faulty recording apparatus, and consequently could not be included in the analysis. A second participant's interview was considered not suitable for inclusion due to transcribing difficulties; the majority of the interview was unclear due to the participants' speech, and content appeared to be largely factual and consisted of echoed memories (i.e accounts based on what others had told him). Despite efforts to extract personal meaning, it was evident that he was not able to comply with my requests. Therefore, a total of seven participants are included in the study. Demographic information can be found in Table 1.

Participants were selected from an AS social group within a rural county. It became apparent that one of the older participants had not been formerly diagnosed; however the decision was made to include him on the basis that he identified with the diagnosis of AS for several years and had been attending the support group for some considerable time. He is currently in the process of trying to get assessed. It is not unusual for adults born before the mid 1970's who meet criteria for AS not to have a formal diagnosis as they were already adults before the syndrome was widely known.

Data Collection

Given the social difficulties typically associated with this population, I attended social evenings arranged for the group in order to get to know members informally. During my first meeting I addressed the group as a whole and introduced the study. Information sheets were provided for those who expressed an interest (see Appendix 3). I made myself available during these events for individuals to approach me with any questions or concerns and to go through the information if they wished. Those who expressed an interest were contacted by telephone and a discussion concerning details outlined in the information sheet took place before appointments were made.

Data were collected through in-depth semi-structured interviews, prior to which consent was readdressed and any questions or concerns discussed. The interview schedule (see appendix 5) was developed and checked with my research supervisor and a second local psychologist who works with adults with AS. Guidance was also sought in terms of making the interview situation as 'autism friendly' as possible. For example, keeping eye contact non threatening and ensuring questions were comprehensive. Following this consultation, a decision was made to give the participants the choice of receiving the questions via email beforehand with the instruction not to discuss responses with family members.

Interviews lasted between 25 – 90 minutes and were completed on NHS premises. Questions aimed to explore the experiences of being parented during childhood and adolescence. This had a particular focus on what they found helpful and unhelpful and how they would have liked things to have been different. At times, questions needed to be simplified and prompts provided (e.g. clarifying the question, asking for concrete examples). However, I remained mindful not to lead the interview in any particular direction.

Before leaving the interview, participants were given the opportunity to debrief and checks were made as to whether the interview had raised any issues for them. They were reminded that they could speak to a psychologist within the service where the interviews were taking place if they wished.

Data Analysis

All interviews were audio taped and transcribed verbatim. Each participant was allocated a pseudonym and any other potentially identifying information removed. Prior to the analysis process, credibility checks were performed on each transcript. This involved sending each participant a copy of their own transcribed interview for checking. This was followed up by an email asking whether they were satisfied with the content of their interview and whether they were happy for me to use the excerpts highlighted. Only one participant responded, and had elaborated on one of his responses. This was added to his transcript. An opportunity to check personally with the remaining participants arose at a social event. All stated they were happy for me to use any aspect of their interview.

The transcripts were then analysed using Interpretative Phenomenological Analysis (IPA). The process of which involved several stages. Each transcript was read several times and analysed individually. The first stage of the analysis involved making preliminary notes in the margins which highlighted initial reflections and summarized significant points and events. The second part of the analysis, which is more interpretative, involved moving to a higher level of analysis in order to gain a more abstract understanding of each person's accounts and to identify salient patterns and themes. At this stage, reflections searched for various meanings that experiences may have held for participants and how these may be understood within the contextual restraints. I also thought about what other possible influential factors may have shaped their understanding and what function particular perspectives may have served for them.

Transcripts were read several times until it became possible to identify clusters of salient themes. Those that appeared related were ordered under subheadings. Throughout this process the analysis was re-checked to ensure that themes and interpretations were embedded in the text. I also used supervision to ascertain this. Additionally, I attended regular IPA research group meetings facilitated by clinical trainees, the purpose of which was to enable cross examination of each others analysis. This offered opportunities for my analysis to be challenged or validated by several other independent researchers.

Initial summary tables were developed for each participant and were checked with the texts. These were then developed further into a list of individual themes and sub themes for each participant (see Appendix 6).These tables were then checked and discussed during supervision and with peers during IPA research meetings. In order to establish a relationship between clusters of themes between participants, colour coded photocopies of excerpts were physically cut up and arranged and re-arranged to establish a visible relational structure. Eventually excerpts illustrating main themes and sub-themes were integrated into an inclusive list of main themes that reflected the experience of the group as a whole (see Appendix 7).

Not all participants were connected to all themes. However within the IPA approach, this is not a requirement (Smith, 2003). The final selection of themes was not necessarily solely chosen for their prevalence within the data but for their richness within the accounts.

Table 1: Participants' Demographic Information

Participant Number and pseudonym	**Age**	**Age at diagnosis**	**Diagnosis**	**Employment status**	**Marital status**	**Living arrangements**
1.Alan	23	14	AS	Student	Single	At home with parents
2. Liam	21	14	AS	Student	Single	At home with parents
3. Tom	28	12	AS	Student	Single	At home with parents
4. Shaun	24	14	AS	Employed	Single	At home with parents
5. Ian	31	16	AS	Employed	Single	At home with parents
6. Terry	57	52	AS	Employed	Divorced	Lives alone
7. Graham	46	-	Suspected AS	Unemployed	Married	Lives with wife and two children

Reflection on the process

Although attempts were made to make the interviews as relaxing and informal as possible, I was impressed by the participants' ability to manage what they may have still considered as an anxiety provoking and intensive social situation.

I was particularly moved by some of the accounts given by participants in relation to their experiences of feeling emotionally deprived and was surprised by how openly some participants were able to discuss some of the more personal and potentially difficult subject areas. I was also surprised at how reflective and emotionally descriptive some participants were; abilities not typically associated with autism.

I drew on my clinical skills to engage and relax the participants and demonstrate empathy during some of the more personal and potentially difficult subject areas. I wondered whether my gender may have also been influential in facilitating disclosure given that that men usually find women easier to talk to about emotional issues (e.g Wagner-Raphel, Seal & Erharat, 2001).

Given my training as a clinical psychologist, I was aware that at times it was difficult to segregate this role, particularly when participants were describing emotive experiences. Being mindful of this enabled me to monitor my responses and refrain from taking a more clinically explorative position, which may have been unhelpful for the participant. I was aware of needing to remain in the role of the researcher and how this differs from one of clinician.

During both the interview and analysis process, I remained mindful of influences and strong opinions within myself which could have influenced my thoughts and feelings. For example, during the interview process a number of participants expressed how helpful they had found physical punishment as a form of discipline; something I strongly disagree with. Whilst carrying out the analysis, I was aware of the emotional impact this had on me and the need to remain focused on the personal meaning this had for the participants which contradicted my own feelings on this controversial issue.

Throughout the analysis process I also considered the possible impact of the broad range of therapeutic approaches encountered in my training as a clinical psychologist, including cognitive behavioural, systemic and psychodynamic therapies. I was aware of the relative influence of these different perspectives during the analysis process and whilst writing the discussion.

Findings:

An Overview

Analysis generated four overarching themes (see Table 2). The first theme, *feeling nurtured and supported*, describes how participants felt parents had supported them with difficulties relating to ASD during childhood and adolescence, and how they felt such experiences had helped them develop as a person.

The second theme, *feeling restricted/held back*, describes contrasting experiences to the first. These are understood as ways in which certain participants have found certain aspects of parenting unhelpful, restricting and confusing. The third theme*, a sense of loss,* provides insight into how some of the experiences reflect a sense of feeling let down and/or emotionally deprived, the implications of which appear to have remained pertinent long into adulthood.

In the final theme, *appreciation of discipline*, participants talked about how firm guidance and instilling a sense of respect had been helpful in providing them with clear guidance in relation to boundaries and structure.

Table 2. Themes generated from the Analysis.

Main Themes	Sub-Themes
Feeling nurtured and supported	• Help with connecting to outside world • Viewing parents as a positive influence • Feeling emotionally supported/contained • Diagnosis: facilitating change and understanding
Feeling restricted/held back	• Diagnosis: undermining a secure sense of self • Parents not providing/understanding what I really needed • Pressure to achieve • Feeling restricted/controlled
A sense of loss	• Missed opportunities in life • Feeling emotionally deprived
Appreciation of discipline	

Feeling nurtured and supported

This main theme encapsulates positive and helpful experiences with parents during childhood and adolescence. The final sub-theme describes positive repercussions of receiving a diagnosis and the difference participants felt this had for them in terms of personal and social development and relationships with their parents.

1a. Help with connecting to the outside world

The narratives of some participants (1,2, 3,4) describe appreciating opportunities and efforts made by parents to help them connect to the 'outside world', and learn to be more socially engaging. There seemed to be an understanding that such efforts were around trying to keep them in touch not just with their parents but with people and society in general.

I think my parents helped me to learn more about myself, and helped me to become more in touch with people, more socially interactive. At times when I haven't been able to make many friends I'd ask my mum, explain to her my situation and she'd tell me what I'd need to know to be more in touch with people, what's going on y'know, she helped me to learn about facial expressions…, they helped me get in touch more with what's going on with people and the outside world, like talking to me about the news because I always seemed to be in a world of my own" (Tom).

" I could talk to them about what I was doing. They both helped me learn about the outside world. They talked to me about other people and how to be like other people" (Alan)

Tom is describing how his parents have helped him develop a sense of self which may include increasing his awareness of his difficulties associated with ASD and social interaction. Both Alan and Tom refer to an 'outside world'. This indicates the extent of the gulf they may have felt between themselves and other people, and is suggestive of feeling separate, confused and disconnected with society and other people in general; almost in an alien sense.

There is also an insinuation within both narratives that parents were seen as a bridge to this outside world, almost like interpreters of a foreign language. In Tom's case, he seems to be saying that explanations his parents gave around social interactions, such as non verbal forms of communication, have helped him to understand his difficulties with friendships and to try to understand and connect with other children.

Tom also refers to his parents talking to him about the news, which he retrospectively understands as helping him understand and keeping him in touch with people, reality and society in general. Alan also seems to indicate that he found information about other people and society in general helpful in connecting to others and remaining in touch with the world. Both accounts indicate a desire to understand, connect and fit in with society.

Shaun describes earlier recollections of his parents helping him to engage.

"They showed me lovely places and took me on holidays and things, they engaged me at all times. I think that was one thing my mum was quite worried about when I was younger, they always engaged me and I never gave anything back and I wasn't acting like a typical kid" (Shaun)

There appears to be a retrospective understanding and appreciation for his parents' constant efforts to engage and stimulate him as a child. His description of himself as non reciprocating and not 'a typical kid' appears to reflect an element of admiration for their commitment given their efforts appeared not to have been rewarded.

All three accounts appear to reflect a retrospective understanding and appreciation of what their parents were attempting to achieve, and that they had developed the understanding that this was necessary, given their autistic tendency to be in a world of their own and sense of disconnectedness.

1b. Viewing parents as a positive influence

This second sub theme describes ways in which some participants, (1,2,4) felt their parents had helped them develop as an individual. This was not only in a practical sense in how they deal with situations but also in relation to values and beliefs.

" I think I take after my mum in the way I act. I followed her lead in things like work, in an understanding that such a person has brought me up in a certain way means I've got a better view point in life" (Shaun)

" Some people who are autistic are thought of as being this solid band, stand up straight person, y'know,[ ]. I've got my dad's logic and his way of thinking and I've got my mum's emotion and I've always found it strange how emotional I can be; I'm a lot more emotional than most men I've come across" (Shaun)

There is a strong sense of admiration in the way Shaun describes how he feels his mother in particular has been a role model to him in terms of his perspectives and values in life. He also seems to feel she has directly influenced the kind of person he has become. He has also been influenced by her role as a special needs teacher in the line of work he himself has chosen to follow; support worker for adults with learning disabilities.

Shaun goes on to describe how he feels he has inherited positive traits from both his parents which he identifies as being complete opposites but both of value to him. What is particularly indicative here is not just a balanced sense of self, but that an emphasis on his own emotionality gives a sense of attempting to distance himself from traits typically associated with autism. This is particularly emphasized when comparing himself with non autistic males in relation to his ability to be emotional. What also comes across in both quotes is a stronger identification with his mother over his father who he had previously identified as also being autistic.

Liam also felt that his sense of values and how he has developed as an individual were related to his upbringing.

"..the great thing is you will never grow up in a background like mine that will make you so content and appreciative of things in life. There's too many people out there who always want more, or want better. With us it's as long as something's good enough then you've got it, which is why I've grown up to be such a nice person. (Liam)

Liam appears to be saying that his background in general has shaped him as a person and taught him the value of things in life. There seems to be an indication that he feels his childhood has not always been easy in a financial sense but that such experiences have led to an appreciation of what he has got and to be content as a person, which he indicates is reflective of his family's values in general.

Below, Alan appears to view his parents as influencing him in a more practical way but there's also a sense of him learning from them to be self aware and mindful of how others may see him.

" my parents have always been careful people. You know always makin' sure that,.. always just checkin' that they're doin' the right thing an'such, so yeah, I suppose that's something they've taught me and I've learned from watchin' them, yer know, just to try to….take care of who I am and how I act and so on really"(,Alan)

1c. Feeling emotionally supported/contained

Many of the participants' accounts reflected a positive perception of how they felt their parents had supported their learning and managed difficult emotions. This is particularly captured by Shaun.

". I think what my parents did well was that they weren't afraid of me giving them hell and crying, erm, they just let me get it all out, 'Cause I'm a great believer in my work, you've got this view that people can't loose their temper, no, you can……Some people I know don't want people to get things out or kids to get it all out or afraid of the kid crying, and my parents just let me properly get all my anger out"

Shaun's reflections illustrate a strong appreciation of the freedom of emotional expression and self discovery and a sense of feeling understood and unconditionally accepted by both his parents. There is also a sense of him having felt secure in being able to release anger, and trusting of his parents in being able to contain him. He seems to feel that the beliefs and values of his parents have shaped and influenced his own way of understanding and meeting the needs of others within his role as a support worker, which includes working with individuals with autism. There is the same value of freedom of emotional expression and of not being afraid of anger.

Below, Liam and Tom also describe a sense of emotional security and containment.

" When I was very young I'd cuddle up to my mum, not all the time, just when I was upset. People with AS are very sensitive. There are times when we get really upset y'know, so if I started crying I'd go and cuddle up [ ] if I was told off for being naughty I'd find it quite comforting afterwards" (Tom)

What is particularly salient here is the suggestion that he sought out and gained comfort from physical affection at times of emotional distress. This appears to have been self initiated and on his own terms, though this was not usual behaviour for him and only initiated when he was upset. In this context there seems to be an attempt to reconnect to his parents after being disciplined through the seeking of reassurance and maybe forgiveness. There is also a sense of fragility and vulnerability in his account, which he seems to try to depersonalize and express as a shared phenomenon.

Liam's account also reflects a recognition and appreciation of parental responsiveness and availability at times of need. Though, he feels that this has mainly been provided by his mother.

" She was the parent who was always there for me. Say I'd been ill, upset or I needed help with something, she's always been the one there.....where as my dad has not always been like that" (Liam)

The above narratives are perhaps particularly striking in that they appear to contradict common beliefs associated with autistic individuals in relation to help seeking and initiation of physical affection.

1d. Diagnosis: facilitating change and understanding

The majority of the participants (1,2,3,5) reported noticing a difference in the way their parents supported and responded to them following receiving a diagnosis. Many of them described a greater sense of feeling understood and helped and that things generally became less stressful. Alan, Tom and Liam received their diagnosis whilst they were still at school. Assessment was instigated following parents' concerns over difficulties and suspecting something was 'different' about their child.

"before I got diagnosed, it was always one of well…sheer confusion really, my parents didn't know really or … figure out what was up with me [ ]after I was diagnosed my parents became a lot more, like, understandin' and err…. and like realisin' of what it was like and I suppose it helped them be a lot more supportive and enouragin' and, err, it made my / it made my family life a lot more secure" (Alan)

" It became a much closer relationship 'cause they realised, they started to understand who I really was, err, what made me tick"(Alan)

In comparing his relationship with his parents before and after receiving his diagnosis, Alan describes an increased sense of feeling understood, not just in relation to his difficulties but as a person and that he felt this had a positive impact on the quality of the relationship. He relates being understood with an increased sense of security in that this sense of enlightenment had facilitated his parents in being able to meet his needs and respect his difficulties, but maybe also in that he is less of an enigma to his own family and to himself.

There were also experiences of feeling less stressed and pressurised to achieve or get things right:

"my life before hand there was always an expectancy of somethin' and if I don't give whatever it is, it's a failing. But, when I got my diagnosis, if something goes wrong, oh, it's the Asperger's or the dyspraxia or what ever I'm diagnosed with, there is actually a reason, it's not your fault. So it's kind of that effect". (Liam)

" I think I got more respect from my dad, he can say I'm not being awkward, I've got Asperger's so, he can see, my, where I erm, look stressed, he can understand that where he might not have been able to before.[ ].it takes the pressure off in a way"(Ian)

Both accounts suggest previous experiences of being misunderstood and blamed for difficulties or 'failings', and that following their ASD being identified, there was a tendency for parents to be more forgiving and accepting of downfalls. Ian particularly notices a change in the way his father perceives him as a person in that he feels more understood and respected. His reference to feeling less pressure is reflective of previous accounts which emphasized the importance he places on being respected by others, particularly his father.

In Tom's account he describes how his diagnosis not only helped his parents to make sense of certain behaviours but, as similarly described by Ian, there was an understanding that certain behaviours were not always within his control.

[my parents] could understand why I kept staring at things and got so obsessive with things like tractors, and also the same with teachers at school. They're were able to tell people at school what was going on and help them to help me . They could understand more about me and why I get so distractible and not listening to what's going on"(Tom)

Terry didn't receive his diagnosis until his mid forties, five years ago. Although his parents had both died he compares how things are for him before and after learning about his Asperger's.

I grew up feeling that I was stupid, that I was below average intelligence, just perhaps good with my hands, or reasonably good, a bit of common sense.
I didn't/I basically thought I was ugly because people didn't seem to want to know me….I wasn't educated very well. (Terry)

I've felt better in that there was a reason behind things, as I say I found out that I wasn't stupid, I was intelligent, which has led me to socialise better I think, particularly amongst very intelligent people, amongst academics. It's also given me another interest, Mensa (Terry)

Terry's account implies that learning about his diagnosis enabled him to retrospectively make sense of the difficulties he had previously experienced, which largely seem to be around identity, such as feeling different and defected in someway. Making sense of things, and particularly discovering he had a high IQ (top 1% of the population), not only had a positive impact on his self esteem and confidence but his self identity. The former narrative suggests feeling a loner and inadequate, whilst the second implies a sense of belonging and fitting in.

2. Feeling Restricted/Held back

This second main theme appears very much to be the 'flip side' of the first theme. Several themes emerged from accounts which reflected a sense of lack of control over decisions and life in general, as well as feeling a lack of independence or a sense of unmet needs.

2a. Diagnosis: Undermining a secure sense of self

Although the majority of participants identified positive consequence following diagnosis, Shaun, who was diagnosed at aged 14, strongly felt that receiving his diagnosis was not his own choice and that he anticipated it holding him back in life.

" My mum pushed for it maybe because people were telling her that her son was stupid or something or there was something wrong with me..if my life had been allowed to run, I wished nothing had happened and that I was left to live my whole life without it".

Shaun seems to be expressing frustration and a sense that his life had been disrupted. His narrative suggests that the diagnosis has had a negative and restricting impact and that he possibly foresees this continuing throughout his life.

"As far as growing as a person, I think I'm quite capable of not going off the rails as such I think I /I was at the age that I was stable and pretty sure I knew what I was doing. I knew who I was and I wasn't / I didn't want to destroy myself or anything" (Shaun)

There is a strong sense from Shaun's narratives that the diagnosis did not add anything to his own understanding of himself and that this was something that was done to him in order to assist the understanding for others or prove other people wrong. If anything, it appears to have undermined an established sense of self. ."*It's very hard if you've already know yourself and worked yourself out"* There appears to be some anger in relation to this as if he perceived it as an infringement on his identity and security and stability as an individual.

Shaun also implies that his dad was against the diagnosis and that he saw it as labeling his son rather than it being of any use.

My dad didn't like it because it became this constant BANG – label, BANG – label, and so on. He's more autistic than I'll ever be but he wont admit it".

He seems to go on to relate this resentment to his father possibly identifying with his autism and that the resentment of his diagnosis is possibly a reflection of his own reluctance to acknowledge his own autism in any way.

2b. Parents not understanding/providing what I *really* needed

The majority of the participants (I,2,5,6,7) described aspects of their childhood where they felt some of their needs had not been met. Although in some cases they were not always able to identify this at the time, retrospectively, increased insight developed during adulthood meant that they were able to look back and identify what was missing or what could have made things easier for them.

" [I would have liked] more affection, more talking, to feel wanted and helped. More attention and I wished I 'd had been diagnosed earlier in junior school, not necessarily for AS for dyslexia that would have made lot of difference, or even if they'd have done an intelligence test on me they'd have known something was wrong" " (Terry)

Throughout Terry's whole interview there were very strong sense of deprivation and unmet needs. He describes during childhood a confused awareness of something missing, or not being right, although as a child he was unable to identify what he really wanted from his parents. As his insight and understanding developed he identified that these unmet needs were very much about having his difficulties acknowledged and investigated and provision of support. There is a strong sense of regret and of feeling unimportant and let down by adults. He places particular importance on wanting to have had his intellectual abilities recognized as a child and a sense that this came to him too late.

There is also a retrospective insight into a need for overt communication of love and affection and social stimulation from his parents.

Graham also went through childhood and adolescence feeling something was different/'wrong' about himself. He acknowledges that his parents tried to help him with the academic side of things but that their understanding of what he needed were very much different from what he actually wanted, which was to help him to socially interact and connect with people in order for him to develop a secure sense of self and build relationships. His reference to their inability to meet such needs reflects a perceived lack of capacity rather than of not caring.

"they helped me with my dyslexia and they tried to get me into university ..but none of it was any use to me because the real life skills, that were really foundational are the abilities to actually interact and seek/ to actually feel that you are a human being and my parents weren't actually able to give me that. ". (Graham)

Liam's account highlights a need for his parents to have provided him with clear and concrete step by step explanations and a desire to have fore warning of physical changes during puberty.

"I never knew what was coming round the corner…a bit like with the relationship thing, as you get older, it would have been nice, if somebody would have said, before you go through puberty and something like that, these changes might happen" (Liam)

There is a clear sense of feeling uninformed about life in general and frustration and confusion relating to lack of awareness of pending events and changes in life. His narrative particularly highlights his annoyance of the perceived lack of information given to him and the resulting confusion which he feels could have been avoided.

This quote highlights the well documented need for concrete step by step explanations and dislike of unexpected events and changes.

For Alan and Ian, there is a perceived lack of availability and support *"well, mum used to go to a lot of Rolling Stones concerts and she was into that whole sixties vibe you know, that whole thing and we were just kind of ignored really as kids, we didn't really have much time with mum and dad, so" (Ian)*

" I could have done with more structure really, there were no rules" (Ian)

Ian identifies that as a child he needed more structure and concrete boundaries around what he should and shouldn't do. There is a distinct perceived absence of parents and a sense that he and his siblings felt unimportant and that his parents appeared to place their own needs above theirs.

Alan's account describes how he felt his parents responded to his distress prior to his diagnosis.

I know they always said so [speak to them] but when I felt that/ so distressed they always seemed quite annoyed with me about it. I mean if..they were or they weren't but they always tried to put me off tryin' to speak to 'em and er…….that's just it, I mean….although it can't be helped really, because, errr, we, me and them, and everyone else never seemed to really know what was up at that point" (Alan)

Alan describes feeling that both his parents found his help seeking and distress difficult to tolerate or manage. There's a sense of feeling dismissed and uncontained and an element of confusion over the apparent discrepancy between what they had said they could provide and what was actually available. He appears to go on to defend their reactions and makes sense of it through attributing a universal lack of understanding.

What appears to be illustrated in all of the above narratives is a sense of being let down, either in relation to availability of support and guidance or assisting with personal development. Particularly for Terry and Graham, there is a sense of prolonged repercussions into adulthood in terms of missed opportunities and developing a secure sense of self.

2c. Pressure to achieve

Some of the participants (2,5,7) described feeling a pressure to meet the expectations of parents, particularly in relation to academic work.

"I think their expectations were so high ..I had a high IQ and so people in the classroom and my parents expected me to do well, and I could do quite well in the classroom but when it came to exams, I kind of couldn't put it all together. I couldn't handle the pressure". (Graham)

" My dad came home with my school report once and he said ' that's disgusting'…I think I was worried about the fact that I was actually trying my best and it still wasn't going well' …….'they should have respected that I have limitations" (Liam)

Both describe feeling that people's expectations of them were too high and that they felt difficulties and limitations were either not being recognized or respected.
Liam's also expressed concern that his best was still not good enough for his parents.
The word 'disgust' has particularly strong connotations of antipathy and disapproval.

Ian's pressure to achieve appears to have been motivated by a need to gain respect from his father and out perform his siblings.

"it still has it's tension there, y' know, who's which one of the children is going to achieve the most y'know and at the moment it's Jess, she's / or I think Dave could go ahead cause Dave's got the ability to design a few buildings, few really nice buildings. (Ian)

Ian appears to be describing a sense of rivalry between his siblings in relation to career achievements and how their successes may be being compared by his parents. He perceives this to have continued into adulthood. There is a sense of competing to please parents and gain respect, which is echoed in other elements of Ian's accounts "*from our point of view it was about trying to win respect from Dad"*. Ian appears to place great importance in gaining respect from his father, which may be about getting noticed and feeling appreciated and a valued member of the family.

2d. Feeling restricted/ controlled

Although only three participants expressed feeling restricted and/or controlled by their parents (2, 6,7), it was a prominent theme for them throughout much of their accounts.

Graham described feeling restricted and controlled by both his parents throughout childhood and adolescence. He understood this to have contributed to his suffering from depression during early adulthood.

"I just felt really controlled. I think my parents lived a really controlled life and part of their control was me and especially my mum. My dad was really anxious about things". (Graham)

"my dad was obsessive really and lived in his own world, and he would take forever. He'd have this little ritual in the morning and we used to go to school, and he's make us late, and then he'd make me late coming home as well. I'd wait for an hour, but he was in his own little world. I think he's kind of on the autistic spectrum somewhere, and I'd be waiting for him..it's interesting…erm, there was this kind of quite controlling thing were my dad was kind of in his own world and I was really secondary/ my needs were not very important really" (Graham)

He identifies his father's obsessive traits and a tendency to live in his own world as mechanisms of control and understands these as his father's attempts to contain his own anxiety through controlling his environment and the people within. There is a sense that he felt invisible as a child and although his father was physically present, he was not experienced as available. There is also an understanding that this anxiety and controlling behaviour may possibly be associated with autistic tendencies; an understanding which may have enabled him to have some sense of connection with his father. It may have also served to externalise his father's behaviour towards him rather than understand it as it being related directly to him. Furthermore, it may be an attempt to confirm his own autism given that he is in the process of trying to get assessed.

Liam also describes a sense of feeling restricted, which appears in the sense of having to gain approval and permission.

"my mum's, one of the reason's why I may live on my own when I'm older.It's because I'd never have to check with her, like I'm a allowed to play rugby?, am I allowed to have a girlfriend?, and so on, or am I allowed to do this?. In the past, I'd take for granted that she'd let me when I was younger but, for some reason now, she seems to, like, no, you can't do this, no, you can't do that, I'm like, you let me as a child, but you don't let me as an adult most of the time".(Liam)

What comes across here is feeling stifled and held back in life. He expresses a need to break free but seems to feel he is currently not ready for this. He identifies a change in his mother's attitude in that she is now more restricting and protective than when he was younger.

Although Terry did not explicitly state feeling restricted, there is a sense throughout his interview of being held back in life. This is illustrated through his descriptions of feeling misunderstood by others, people failing to recognize and nurture his true potential, and a home life characterised by social and emotional deprivation.

3. A sense of Loss

The third main theme encapsulates a strong sense of loss reported by many of the participants in relations to their childhood (2,4,5,6,7). Sub themes within describe various ways in which they experienced this, with the latter theme relating more to the associated feeling of unfairness.

3a. Missed opportunities in life

Several of the narratives conveyed a sense of having missed out on chances to achieve and develop skills and knowledge.

Terry was diagnosed with AS five years ago, during which he also learned that his IQ fell within the top 1% of the national average and that his difficulties experienced throughout childhood were related to autism. He had reported having felt 'stupid' and 'below average' throughout his life.

"[I feel] a bit of anger that I might have done a lot more with my life…I was being told that this level of intelligence is what professors have at universities and things like that. I suppose there is a certain amount of anger that if I'd have been diagnosed when I was young, something could have been done to educate me more" (Terry)

Terry's extract illustrates anger and regret and a strong sense of what could have been. There is the impression that he feels much of his life has been wasted and that the assessment came too late in life. He implies that people had let him down during childhood and that things could have been a lot different for him in terms of recognizing and nurturing his talents.

Shaun seems to feel that he wasn't given enough responsibilities when he was younger and that he would have liked more independence and the opportunity to have learned certain life skills rather than having had these done for him.

"There's so many things I'd wished I could have done, y'know, just if I'd been given a chance to learn things mechanical, musical or domestic. If I'd have been given things to do when I was younger…in terms of helping me with my car, cooking or anything, I feel it's difficult to learn now" (Shaun)

The above extracts illustrate how both Terry and Shaun feel that opportunities were missed due to other people not providing opportunities or hindering their development in some way. Both illustrate a strong sense of regret and it all being too late, and seem to feel that implications of this have impacted on them into adulthood.

Liam's account differs slightly in that he seems to feel that he himself is responsible for having missed out on achieving more in life. He feels that his fantasies of being famous and being out of touch with reality has meant he has missed out on realizing and achieving his full potential.

"I didn't realize that I spent most of my life in a world of my own, which has cost me dearly. If I'd have lived more in reality I probably would have achieved a hell of a lot more than what I have" (Liam)

3b. Feeling emotionally/socially deprived

Accounts from the two oldest participants strongly imply a developed insight into a need for affection and emotional connection with their parents during childhood. It was strongly evident throughout their interviews that they felt that relationships with both parents were inadequate in meeting their needs, particularly in terms of developing a secure sense of self.

" I didn't have much of a relationship with my mother. I can't remember being hugged, kissed or anything. There was not even any sort of social interaction" (Terry),

" I don't remember talking much to them. I knew I used to ask me mum how to spell things because I couldn't spell properly. I can't remember talking to me dad much either. I don't feel we had a relationship really. He was there, he didn't do anything for me other than let me scrounge his dinner"(Terry)

Through both narratives there is a distinct sense of feeling uncared for, unimportant and unloved. The first quote suggests a feeling of maternal deprivation and a desire to have had physical affection from his mother, at least as an overt communication of love. He conveys an understanding that his relationship with both parents lacked any kind of depth and that communication and contact seemed to just serve a practical function. In trying to make sense of this, Terry expresses a suspicion that his mum may have also had AS: – *"I do wonder whether this sort of Asperger's came down her side of the family",*

Graham also refers to a desire for physical affection. In the first extract he describes a sense of trauma following his father's withdrawal of affection, which is conveyed in his emphasis on the vividness of the memory. He seems to have understood this as a form of rejection, not just of him as a son, but as a child.

" he used to tuck me up in bed and give me a kiss goodnight up to the age of six and I CLEARLY remember the day when he said ' oh, you're too old to give a kiss to'. I was really, really hurt by that and that was the age of about six. And I can remember that now. It was absolutely horrific". (Graham)

"When I was a teenager I remember when about…eighteen, no ones ever touched me for years….years and years and years. I hadn't been touched.. No one's put their hand on my shoulder or anything (Graham)

Graham's description of how he felt in adolescence conveys a sense of defectiveness and feeling rejected by the world. A sense of isolation and feeling disconnected is also conveyed along with a need for physical contact. It may be that he equates physical contact with being connected to and accepted by others.

4. Appreciation of discipline/firm boundaries

Several of the participants, (1,3,4,5) spoke positively about how their parents disciplined them and tended to appreciate and value structure and firm clear communication of 'rule' breaking. For Alan and Ian, there appeared to be an appreciation of physical discipline.

"my parents, were never afraid to smack me, although I think in hindsight that was a good thing, it sort of taught me to not, well, to listen to my parents really, I mean I know in now days, political correctness an' all that, it's a lot...people are a bit more afraid to, or hesitant to discipline their kids in case they get the council round or.../ ne.r My parents were / my parents were quite strict with me when I was younger and err, that taught me, in a sense to make sure I listened to em' (Alan)

There is an indication that Alan perceived his parents as fairly authoritarian, yet his reflection back on this appears to suggest developed insight during adulthood into what it was his parents were trying to achieve. His account illustrates awareness of the controversial nature of physical discipline but he seems to retrospectively appreciate his parents' attitude towards this and feels that this helped him to develop a sense of respect towards them. This view is echoed by Ian.

"my dad used to cuff us. I think that was fantastic, cause it set a limit for us, a clear guideline. I think kids today aren't allowed to be cuffed. I think that's the difference today between Victorian children who were correct and well brought up and modern children who are just vandals running a mock, you know, urban [ ]It gave us a structure, it allowed us to know right from wrong really.(Ian)

Ian clarified during the interview that ‘cuffing’ meant a slap around the back or side of the head. He clearly experienced this as beneficial to him in that it provided clear boundaries and a served as a concrete and reliable indicator of doing something wrong. There is also a sense of respect and admiration towards his father. His perception of current parenting methods as being inadequate suggests that lack of firm physical discipline is associated with delinquency.

It is important to note that although some participants found physical discipline helpful, this is something I wouldn’t condone. It could be that this form of discipline served a very clear communication of crossing boundaries and helped them to know where they stood.

Shaun’s reflection on his parents’ sense of discipline illustrates an appreciation of the balance between giving him the freedom of experiential learning and self discovery, whilst maintaining firm boundaries and keeping him safe. There is also an expression of trust and admiration and that such experiences have shaped him as a person.

“in life you learn and learn and learn and you learn what’s right and what’s wrong and so, my parents taught me, well, let me find out what was right and what was wrong. They told me when I was doing something wrong..... when you’re really doing something silly, when you’re doing something that will get you into trouble, erm then they told me off. That’s solid, that’s important”(Shaun)

When asked about general advice to parents of children with AS, Tom’s response focused on discipline. What he suggests clearly reflects his own experiences.

“we can be sort of sensitive at times, so if you’re going to tell them off, try not to be too harsh, it’s always good to discipline them, but be sensitive if you can be aware that we don’t always know what’s going on a lot of the time. [ ] When I was young , I used to get told off by my parents or by other people, I’d get upset y’know. I didn’t like them shouting at me , they used to smack us as well.[ ] At the time it made me feel very angry. I think it might have been helpful at the time as it would stop me from doing the same thing again” (Tom)

His narrative illustrates a sense of fragility and sensitivity but as previously, he depersonalizes this and expresses this as shared with all people with AS. He describes his dislike of being shouted at which may be associated with sensitive hearing commonly reported in autistic children. However, his description in a previous quote in which he describes seeking physical comfort and affection from his parents after being told off, implies an emotional sensitivity related to perceived rejection or negative evaluation from others.

Although he retrospectively perceives his parents' attempts at disciplining him as having been effective in its aims, he implies that at the time it felt unfair in that there could often be a lack of understanding that what he was doing was wrong.

Discussion

This study explored the childhood experiences of individuals with AS specifically focusing on their relationships with their parents and their views of how they were parented. Two key overarching themes to have emerged appear to reflect contrasting experiences; *feeling nurtured and supported* and *feeling restricted/held back*. There is a sense of conflict/ambiguity as some of the younger participants' accounts reflect both positions. This suggests an internal struggle relating to the transition into adulthood in terms of a desire for more independence and responsibility versus the desire for continued adult supervision and security.

Participants described a number of ways in which they felt helped and supported in terms of their development as an individual but also in coping with difficulties related to AS. This included feeling emotionally contained and nurtured as well as supported in a practical sense.

Support and encouragement with social skills, understanding people and connecting to the 'outside world' were commonly reported. Individuals with autism are described as being 'in a world of their own' both by researchers (e.g Gillberg, 1998) and in personal accounts (Grandin, T, 1995). Parents were described as bridging a gap to the outside world through helping their child to connect to society and other people. This was facilitated through help with forming relationships with peers, encouraging interest in current affairs and providing explanations around social interactions and non verbal forms of communication.

Despite difficulties in forming and maintaining friendships, AS individuals look for interactions and seek friendships even from an early age (Eisenmajer et al, 1996). Social experiences are a fundamental factor influencing whether a young person develops a sense of belonging or isolation and can significantly impact the early adolescent's self perception (Gutstein and Whitney, 2002). This was very much evident in the accounts of the two older participants who reported the absence of such opportunities. Both retrospectively recognized a need for their parents to have interacted with them more often and to have provided encouragement and opportunities to develop social skills, build relationships and develop a secure sense of self. This highlights a need for both parents and therapists to acknowledge this vulnerability, and provide consistent opportunities and support for social development.

There appeared to be a distinctive understanding and appreciation of what parents were attempting to achieve through their parenting strategies. Several participants reflected on how they felt their parents had shaped them as individuals and influenced their perspective on life. The sense of feeling emotionally supported, understood and contained was evident as was a tendency to seek support and physical affection at times of emotional distress. One person expressed how much he valued his parents' efforts to constantly engage him as a child, as well as having had the freedom to express his anger, and experience learning through exploration and self discovery. There was the sense that he felt contained and safe enough for this to be possible. There were also reports of how feeling understood by parents made participants feel 'safe' and 'closer' to them.

Findings could be perceived to support research within the area of attachment relative to autism, which suggest that these children can display secure attachment behaviour towards their caregiver (Rutgers,Bakermans-Kranenberg, van IJzendoorn, and van Berckelaer-Onnes, 2004). Taylor et al (2008), proposed that while social impairment may interfere with the formation of secure attachments, children with higher cognitive abilities are somehow able to compensate for this disruption.

Some participants perceived their mother as the main source of support during childhood and adolescence. This is congruent with adolescents in general who report feeling closer to their mothers (Buhrmester and Furman, 1987), and spend more time interacting with them (Larson ,Richards and Perry Jenkins, 1994).

Accounts seem to conflict with reports from researchers who note that children with AS tend not to seek physical closeness at times of distress and to not seek assistance from others for their problems (Attwood, 2006; Dunn et al, 2002). Two older interviewees recalled a distinct absence of physical affection from their parents. This absence of affection was felt to be detrimental to the development of a secure sense of self, and gave them a feeling of defectiveness.

Both of these older participants went through childhood without a diagnosis and reported feeling detached and misunderstood by their parents. They also reported experiencing negative beliefs about themselves during childhood which they had attributed to their difficult relationships with their parents. Theories around the development of negative self perception have highlighted the role of parent-child interaction, including poor attachment and parenting style (Alloy, 2001, Chiariello and Orvaschel, 1995).

Both participants felt that at least one of their parents was also on the autistic spectrum and recalled inadequate communication and lack of affection. Wall (2003), notes that parents with ASD tend to have difficulties placing the child's needs before their own and may not be in tune with emotional and social needs. Attwood (2006), states that individuals with AS can make good parents, however, there is a need to provide extra support to help them meet their child's needs. Psychological intervention could assist with becoming more in tune to the emotional needs of the child and providing education in how to express love and affection.

The majority of participants felt that receiving a diagnosis enhanced their parents' understanding, which in turn resulted in more effective support and guidance. In a survey of 109 parents of children newly diagnosed with an ASD, Mansell & Morris (2004) found that 87% reported that they were more able to understand and help their child, while 74% said that they felt more able to adapt family life to the child's needs and behaviours. Huws et al (2008), explored first hand accounts of young people with AS in relation to their experience of being diagnosed. Many of her participants reported similar perspectives in that being able to place difficulties and certain behaviours within a context, and to have an understanding seemed to lead to more effective parenting in the eyes of the child, and a feeling of being understood.

Some participants reported noticing a difference, not just the style of parenting but the quality of the parent-child relationship. This sense of being understood seemed to produce a feeling of containment, closeness and trust. This particular finding is comparative to reports from Samio, Pakenham and Sofronoff (2008), who quantitatively explored sense making in parents of children with AS. They found that having someone explain the nature of AS and help them to understand the child's perspective can enrich and improve the quality of the parent-child relationship.

Participants' accounts strongly highlighted the importance of early diagnosis, not just in terms of helping the individual make sense of themselves, but in assisting parents to access information and resources to help them to fully understand the difficulties experienced by the child and to provide the necessary support.

However, the benefits of diagnosis were not felt by all. One person reported that while it provided his mother with enhanced understanding, he felt it was an unwanted label that conflicted with his already established sense of self and made him vulnerable to negative prejudgments from others. Such views have also been reported in Huws et al, in which some of the participants also expressed anger at being 'labeled' and felt that this disrupted plans for their future.

This highlights the importance for health care professionals to be aware of the individual's feelings towards receiving a diagnosis and to explore and discuss with the family and the person advantages and disadvantages of receiving a diagnosis in order to facilitate an informed decision. Pre diagnostic counselling is adopted in other areas of health care, such as dementia and HIV (Williams, 2004).

There was also a perceived lack of control and feeling restricted or held back in some way. This was illustrated through descriptions of ways in which participants felt their needs had not been met and/or understood. For some this was accompanied by a sense of loss, as connections were made to having missed opportunities in terms of achievements, learning skills and generally reaching their full potential. In some cases these issues were associated with unawareness of their diagnosis.

Although only one person reported experiencing confusion about sexual development this is a crucial role within parenting and perhaps an issue of confusion commonly experienced by adolescents on the spectrum. The frustration reported highlights the need for parents to be open and honest about sexuality and to provide explanations about changes to expect in relation to puberty. The importance for parents not to assume understanding and awareness, and the need for clear explanations and step by step instructions in relation to all areas of life is well documented both by researchers (e.g. Attwood, 2006), and in personal accounts (e.g. Jackson, 2004).

The findings presented are not intended to be a definitive representation of the views and experiences of adults with AS but provide some insight into what was found helpful and unhelpful in terms of experiences of parenting during childhood and adolescence. Guralnick (2004), reports that for all children, the quality of the parent-child interaction, opportunities for developing social development, and the health and safety provided by the family are fundamental for optimizing the child's development. Consequently it is important for services to provide support for those who care for children diagnosed with autism to identify and meet such needs.

Strengths and limitations of the study

There has been little research that aims to explore first hand accounts of people with AS and non which have explored views and experiences of parenting during childhood and adolescence. The initial focus of the study, family life and relationships, was broad. While a key advantage of this was a diverse overview of perspectives and experiences, a wide focus meant that there were some themes which held limited information and could have been explored further had the initial research question been more focused. Due to the richness of the data, only parenting experiences have been analysed, other experiences elicited in the interviews will be reported in future studies.

Occasionally, participants' understanding of the question was concrete, although this was much less frequent than anticipated. Although I observed that participants managed well with the openness of the questions, conducting a number of pilot interviews, or discussing the interview schedule with a focus group of individuals with AS, may have been helpful in refining the phrasing of the questions and techniques used.

Although participants represented a broad age range, the majority were under 25 years old. Age appeared to play a large role in their narratives, in that the younger participants grew up in a time when AS was more likely to be recognized and diagnosed. With hindsight, the recruitment of a larger sample of older participants may have provided a wider range of accounts to reflect the possible differences made by awareness and understanding. Furthermore, the sample lacked gender and cultural diversity. Inclusion of female and ethnically diverse participants would have possibly uncovered themes related to factors pertinent to these groups.

Clinical Implications

Through obtaining retrospective accounts from adults that reflect their views, wishes and challenges in relation to experiences of being parented, we can gain an idea of how, as professionals, we can focus interventions to support parents in meeting the needs of children and young people with ASD.

A key issue appears to be the importance of early detection of ASD in children. Following this, parents may need help in understanding the child's diagnosis and how exactly it will impact on social, communication and cognitive abilities. Additional work may be required in relation to helping parents to learn and understand complex patterns of emotional communication in order to respond and meet their child's emotional as well as practical needs appropriately. A further issue raised in the study is the importance of communicating love and self worth in ways that are comfortable and understood by the child. Both these points are crucial in nurturing the development of a secure sense of self and awareness of caregiver availability.

Clinicians also need to be aware of the possible psychological impact that receiving a diagnosis may have on the young person, (e.g. in relation to identity and self esteem), and to explore with them their concerns about anticipated implications for the future. This may be particularly pertinent for older children who are receiving a relatively late diagnosis. Clinicians would also need to look out for any strong negative reactions in parents, such as grief and self blame, and to provide support in addressing these issues in order to facilitate optimal parenting.

Additionally, clinicians must highlight for parents the importance of resisting the urge to over support/over protect their child/young person, and to help them find a balance that can enable the young person to develop independence and self efficacy whilst feeling supported. Finally, some of the participants reported that they found physical discipline helpful in that it served as a clear communication. It would not be appropriate to encourage parents to employ physical discipline. However, the current findings inform us as a profession of the importance of working on issues such as discipline this informs us as a profession of the importance of working on issues such as discipline in order to help parents to find more appropriate ways of achieving this.

Conclusion

It is felt that through exploration of first hand accounts this study has contributed to increased insight into the personal world as experienced by individuals with AS. A further aim was to illustrate how reflective such individuals can be, contrary to popular belief. Through demonstrating this, it is hoped that further exploration of personal accounts of people with AS / HFA will be undertaken in order to extend the qualitative literature in this area and further people’s understanding of the world as experienced by this population.

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Appendix 1 – Public Briefing paper

The briefing paper describes two separate studies. The first is a literature review investigating the efficacy of using Cognitive Behavioural Therapy with individuals with Asperger's syndrome. The second paper is a qualitative study exploring the retrospective accounts of adults with Asperger's syndrome in relation to their experiences of parenting during childhood and adolescence.

Literature Review

Introduction

Cognitive Behavioural therapy (CBT) is widely considered as the primary psychological treatment for such disorders. The current literature review evaluates all studies known to have been conducted around the use of CBT with adults and children on the high functioning end of the spectrum (with a diagnosis of Asperger's syndrome or high functioning autism) who have a secondary mood disorder. A particular emphasis was placed on error-orientated CBT' which concentrates more on making psychological changes as opposed to 'deficit orientated CBT' which is more concerned with teaching skills and maintaining on-task behaviour, and is largely derived from the self instructional literature.

There is growing evidence that individuals with Asperger's Syndrome have higher than expected rates of developing a mental illness, typically anxiety and depression. This vulnerability is discussed in relation to a model presented by Gaus (2007) who suggests that various difficulties experienced by individuals with AS/HFA are caused by neurological differences in the way that social and non social information are processed (Klin, Jones, Schulz, Volkmar, and Cohen, 2002). The model illustrates the relationship between cognitive dysfunctions associated with AS and the problems commonly reported, and demonstrates vulnerability points for the development of maladaptive schemas, which can lead to the development of mental health difficulties such as anxiety and depression.

A total of eleven papers were reviewed, which consisted of 7 case studies and 4 randomized controlled trials. All studies were evaluated using quality assurance checklists which assessed aspects of the studies' theoretical basis, design, measures, analysis and results.

Summary of Findings

Several modifications were made to the theoretical framework of CBT across all of the studies reviewed. These included incorporation of special interests and metaphors, clear structure and goals, increased use of visual material, and visual monitoring systems. In order to meet individual needs and abilities, some of the studies reported simplified cognitive techniques and an emphasis was placed on behavioural strategies, such as graded exposure and response prevention. Given this, it is discussed as to what extent techniques used remained within a true cognitive behavioural framework. Adherence to the CBT model is discussed in relation to work by Sturmey (2005).

It is concluded that the research reviewed offer some evidence that implementation of CBT interventions with individuals on the high functioning end of the autistic spectrum can help them develop skills to improve psychological wellbeing. However, few studies adhered to rigorous research standards, which reduce confidence in results. Given methodological limitations and the general paucity of research available conclusions as to evidence of efficacy in using this approach with this client group in relation to mental health difficulties remains uncertain.

Future areas for research are suggested, such as exploring whether people with AS/HFA have the cognitive skills required to undertake cognitive behavioural therapy, such as the ability to recognize emotions, link events and emotions and recognize cognitive mediation. This is based on existing research by Dagnan and Chadwick (1997,2000) who explore this area with people with a learning disability. A further suggestion for research is to qualitatively explore the experience of anxiety and change in individuals with AS, and their actual experiences of CBT interventions.

The Empirical paper

Background and aims of the study

This study retrospectively explores the experiences of individuals with Asperger's syndrome in relation to their experiences of being parented during childhood and adolescence. Although there is extensive research examining experiences of parents in bringing up a child with autistic spectrum disorder, there is a paucity of research from the perspective of individuals themselves, particularly those with Asperger's syndrome, a form of high functioning autism.

Although the etiology of ASD is neurobiological in nature, variations in parenting behaviours appear to influence the subsequent development of children with ASDs (Carter et al., 2007; Siller and Sigman, 2002).

Given that successful family interactions require socio-emotional skills that are limited in children with ASD including AS/HFA it is plausible to consider that family interactions may have different degrees of impact on children on the autistic spectrum in comparison with other groups.

Method

Participants were seven adult male with Asperger's syndrome who were interviewed about their experiences of parenting during childhood and adolescence. Data was analysed using interpretative phenomenological analysis, which involves two stages of analysis. The first stage is phenomenological in that it remains close to the experiences and meanings described by the participants. The second stage is more interpretative and allows for a deeper level of interpretation, for example, drawing on psychological theories.

Findings

Four main themes were generated form the analysis process. These were: *feeling nurtured and supported*, which describes how participants felt their parents had supported them with difficulties relating to ASD during childhood and adolescence, and how they felt the relationship with their parents had helped them develop as a person; *feeling restricted/held back,* which was understood as ways in which the participants have found certain aspects of parenting unhelpful, restricting and confusing; the third theme, *a sense of loss* provides insight into how some of the experiences reflect a sense of feeling let down and/or emotionally deprived, and the final theme, *appreciation of discipline* illustrated how participants found firm discipline and instilling a sense of respect helpful in providing them with clear guidance in relation to boundaries and structure.

Discussion and possible implications for clinical practice

Participants described a number of ways in which they felt helped and supported in terms of their development as an individual but also in coping with difficulties related to AS. This included feeling emotionally contained and nurtured as well as supported in a practical sense. Findings could be perceived to support research within the area of attachment relative to autism, which suggest that these children can display secure attachment behaviour towards their caregiver (Rutgers,Bakermans-Kranenberg, van IJzendoorn, and van Berckelaer-Onnes, 2004). In other areas accounts conflict with reports from researchers and clinicians, who note that children with AS tend not to seek physical closeness at times of distress and to not seek assistance from others for their problems (Attwood, 2006; Berthoz and Hill, 2005; Dunn et al, 2002)

The majority of interviewees felt that receiving a diagnosis enhanced their parents' understanding, which had in turn resulted in more effective support and guidance. Older participants who went through childhood without a diagnosis described the effects this had had on them as well as difficulties encountered in terms of parenting strategies.

Themes generated also illustrated ways in which participants felt their needs had not been met and/or understood. In some cases these issues were associated with unawareness of their diagnosis.

Participants' accounts strongly highlighted the importance of early diagnosis, not just in terms of helping the individual make sense of themselves, but in assisting parents to access information and resources to provide the necessary support.

This study illustrated how reflective and emotive such individuals can be. It also highlights the importance of early diagnosis and how professionals can focus interventions to support parents in meeting the needs of children and young people with ASD in ways that might facilitate the development of a secure sense of self and psychological well being.

Appendix 2 - Ethics and R&D correspondence

(available hard copy only)

Letter from Dr Brendon Laverty, (Assistant Director, Research & Commercial services,) confirming provisional sponsorship from The University of Birmingham. (available hard copy only)

Letter from the R&D ethics board granting approval of the study. Some suggestions for minor changes are also proposed. Available hard copy only.

Appendix 3 – Participant Information Sheet

INFORMATION SHEET FOR PARTICIPANTS

Study Title: Experiences of people with Asperger's Syndrome: A retrospective exploration into home life and family relationships during childhood and adolescence

You are being invited to take part in a research study, which is being conducted as part of a Doctorate qualification in Clinical Psychology. This study is being conducted with the University of Birmingham and South Staffordshire and Shropshire Healthcare NHS Foundation Trust.

Before you decide you will want to know why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The main purpose of the study is to develop an understanding of the challenges and experiences faced by people with Asperger's Syndrome during childhood and adolescence concerning home life and family relationships.

There is a lack of research that looks at the real life experiences of living with Asperger's syndrome. This kind of research can help health care professionals learn more about the experiences encountered from the individual's perspective; what was good, what was difficult, and how you may have liked things to have been different.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You will be given this information sheet to keep. If you decide you would like to help with the study, you will need to contact me within two weeks. You will then be asked to sign a consent form. **You are still free to withdraw at any point of the study without giving a reason and there will be no consequences to deciding to do this.**

Will I receive any payment?

You will get any travel expenses reimbursed and will be paid £10 for participating in the interview.

If I agree to participate what will happen?

If you would like to take part the following things will happen:

- If you decide you decide to take part, you need to call the telephone number at the bottom of this information sheet. You can leave me a message with the secretary and I will contact you to arrange a time for us to meet. When we meet, I will ask you to sign a consent form which says you understand all the information in this ‘Participant Information Sheet’ and that you are happy to take part in the study. You can still change your mind after signing this if you want to. We will then start the interview if you are happy to.

- The interview will last between one and one and a half hours. This can take place in a private room in the Adult Learning Disability Service, in Telford, or you can suggest another place if it will be easier for you, such as your own home. I will need to audio tape record the interview, with your consent. For this I will be using a small hand held tape recorder.

- The interview will be like an informal chat. I will be asking about your experiences of home life and family relationships during your childhood and teenage years. You do not have to talk about anything you do not want to and can choose not to answer questions you feel unhappy answering. I would also be interested in anything else you would like people to know about your experiences of having the diagnosis of Asperger’s syndrome, good points as well as bad points.

- You will receive £10 in cash immediately after the interview and reimbursed of any travel expenses.

- With your permission, I would like to tape record the interview. The recording of your interview will be stored securely and accessed only by myself and my Academic Supervisor – Biza Kroese (Consultant Psychologist, Adult Learning Disability Services). No one else will be listening to your interview and your name will not be used.

- I will be typing up your interview. If you would like, you can read through this. If you are not happy with anything, you can let me know and I can change it or take it out. Any information which could identify you will be removed or changed.

- It is expected that the study will be submitted for publication in a relevant journal.

Are there any possible disadvantages of taking part?

If you find the conversation difficult at any point you will be given the options to either:

- Continue with the interview
- Continue but change the topic of conversation
- Take a break
- Stop the interview

Although it is not anticipated that the interview will cause you distress, if you would like to speak to anyone at any time about any uncomfortable issues, you can contact me, Suzanne Parry, the researcher, or Dr Biza Kroese, Consultant Psychologist, by phoning the Learning Disabilities Service at Tan Bank. Either of us will be happy to talk to you and, if necessary, counselling can be arranged at the service with a professional therapist or counsellor, if you'd like.

What are the possible benefits of taking part?

Besides a small token payment for your time, there are no direct benefits to you. However, this is an opportunity to help develop and expand this type of research, which reports personal accounts and experiences of individuals with Asperger's Syndrome. This can help other people, for example, professionals such as psychologists and teachers, understand the experiences of having AS, particularly concerning children and adolescents with AS who may not feel able to discuss or articulate how things are for them.

What about confidentiality?

Your participation will be completely anonymous. You will be given a false name for the write up of the interview in which all other identifying information (such as your home town, school, age) will be removed. All information will be stored in a locked cabinet on NHS premises. Taped interviews will be identified by code only rather than your name.

What should I do if I would like to take part?

If you decide that you would like to take part, please do the following:

- **Telephone The Adult Learning Disability Service on ………………..**
- **Leave a message for me, Suzanne Parry, saying that you are interested in taking part in the research project**
- **Leave your name and contact details and I will contact you as soon as I get the message.**

I will then meet with you to go through the consent form. If you would find it helpful to meet with me to talk about the research before you make a decision, I would be more than happy to do this. Just mention this in your message to me when you call the number above.

Thank you for taking the time to read this information sheet.

Suzanne Parry

Appendix 4 –consent form

Centre: Birmingham University
Study Number: 08/H1203/31
Participant Identification Number :

CONSENT FORM

Title of Project:

Experiences of people with Asperger's Syndrome: A retrospective exploration into home life and family relationships during childhood and adolescence

Name of Researcher:

Suzanne parry, Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read and understand the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of information collected during the study, may be looked at by individuals from Birmingham University or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the interview transcripts ☐

4. I understand that the interview will be audio taped and I give permission for this. ☐

5. I am happy for sections of my interview to be quoted in the final report and understand that all identifying information will be changed. ☐

6. I agree to take part in the above study. ☐

________________ _________________ __________________

Name of Patient Date Signature

__________________ _________________ ____________________

Name of Person Date Signature taking consent

Appendix 5 - Interview Schedule

1.To begin with, can you tell me about your family?

- Who is in your family
- Do you live at home
- Who do you get on best with – kind of relationships have now in adulthood with main family members (particular parents)

2. What was growing up in your family like?

3. How, if at all, would you have liked things to have been different at home?
(if need prompt -what would have made things easier? or ask what was helpful and unhelpful)
4. Can you describe your relationships with your parents as you were growing up?

5. Can you tell me what, if anything changed at home following receiving a diagnosis ?

6. Can you tell me how your parents helped you through any difficult times
– what was helpful / unhelpful

7. Can you think of a situation you usually found difficult in your family when you were younger?
(– how did it usually effect you, how cope with this?)

8. How do you think your relationships with your parents has influenced you as an adult? –

9. What is the most important advice you can give other parents of children who have Asperger's Syndrome?

Appendix – 6 Initial Clusters of Quotes for potential Themes. Participant 4

Feeling over supported/lack of independence

“I find that she does too many things for me.I’m useless at washing or anything, but I’ve got to learn. She’s not switched on enough at times to realise quite how much she doesn’t need to support me”

“ I do things in my own time I have a strange system but I’ve been finding that she’s [mum] been doing things before I need them done and it’s like, I can do them’..

,…

“ I really need to learn to do more and I don’t simply because it’s been done before me. If I’d have had more responsibility put on me I wouldn’t be at 25 still saying this, I would have kicked on and done stuff”

“I haven’t been able to learn to do things simply because I haven’t had the chance”

You’ve got to find a place for them to grow..be proactive…people mistake proactive for over protective

Missed opportunities

I do feel that at my age I’m a little set and I partly kick myself into doing things I should have done when I was younger.

I haven’t been able to learn to do things simply because I haven’t had the chance. I feel that if I’d been in a more / If I’d have had more responsibility put on me I wouldn’t be at 25 still saying this, I would have kicked on and done stuff”

“I haven’t been able to learn to do things simply because I haven’t had the chance”

“ There’s so many things I’d wished I could have done, y’know, just if I’d been given a chance to learn things mechanical, musical or domestic. If I’d have been given things to do when I was younger I would have accepted it more now. I don’t know if it’s/ …in terms of helping me with my car, cooking or anything, I feel it’s difficult to learn now”

Diagnosis – undermining a secure sense of self

“ My mum pushed for it maybe because people were telling her that her son was stupid or something or there was something wrong with me..if my life had been allowed to run I wished nothing had happened and that I was left to live my whole life without it”

‘As far as a growing person I think I’m quite capable of not going off the rails’ ‘I knew who I was , I didn’t want to destroy myself or anything’,

“ I’m not one of those people who sat there and thought ‘oh wow, I’ve got a diagnosis, it’s great, go back, still haven’t got any friends but look my diagnosis is here!..If you grow up with something and you don’t know it, it’s ok, I would have almost preferred not to have had the diagnosis.”

“ As far as Asperger’s diagnosis, it didn’t mean anything to me. It’s very hard if you’ve already know yourself and worked yourself out”

“The problem is, if you get it early then people have a different perception of you”

“ The thing with a disability is that people will either prejudge you as being rubbish or prejudge you as being needy…they’ll make up reasons why you can’t do something, or they’ll overly support you and never allow you to actually show yourself”

Perceiving parents as positive influence

“ autistic people are thought of as being this solid band stand up straight person almost the emotional an stupidity to the logic. I’ve always valued the two; I’ve got my dad’s logic and his way of thinking and my mum’s emotion. I’ve always found it strange how emotional I can be”

“ I think I take after my mum in the way I act. I followed her lead in things like work..because she started off when I was young, she was a special needs teacher and I followed on understanding that such a person has brought me up in a certain way means I’ve got a better view point in life”

Feeling supported/emotionally contained

I think what my parents did well was, and this is looking at what other people do when bringing up their kids, was that they weren’t afraid of me giving them hell, they just let me get it out, ‘cause I’m a great believer in my work you’ve got this view that people can’t loose their temper, no, you can, because you can definitely let it all out in one go. Some people I know don’t want kids to get it all out, or are afraid of the kid crying, and my parents just let me get it all out properly

My relationship with my mum has been that she’s always been there. She’s always , always been there for me.

They showed me lovely places and took me on holiday and things. They engaged me at all times. That was one thing they were worried about when I was younger, they always engaged me and I never gave anything back and I wasn’t acting like a typical kid

My mum’s pushed my confidence quite a lot..so has my dad, but I don’t think I’m being pushed enough I pretty much decided who I wanted to be, the good things about my parents is that they do tend to let me make my own decisions

They were rewarding in the right way, never overboard

Support with difficulties at school

My mum had to go into school and speak to my teachers because they had this view that they knew what they were doing…What my mum pretty much thought was that school had to accept certain things[ ] she was proactive and she would bang on at the teachers about it and erm, she’s help me out with school work and my understanding of certain things.

I guess if you've had a crap time at school you're not going to be very happy and they gave me enough time to / cause I think the last thing you want when you're being bullied at school is to come home and have a lot of things happening. You want to go home, go back and you want to sit down and it's one of those autistic traits is that you sit down and you don't have to / mum says it's processing time If I disengage my mind from my eyes, just watch TV or play a game on the computer, I would relax and everything would have sunk in and I would have understood it afterwards, so they gave me the right amount of time.

Appreciation of Discipline/boundaries

In life you learn and learn and learn and you learn what's right and what's wrong and so, my parents taught me, well, let me find out what was right and what was wrong. They told me when I was doing something wrong….. when you're really doing something silly, when you're doing something that will get you into trouble, erm then they told me off. That's solid, that's important

They gave me the right amount of attention. They taught me the rules when I was younger.that I lived by each day, sort of, .they allowed me to understand that just because I'm hunting for attention, doesn't mean I'm going to win all the time, it now means that I really dislike it when people do something for attention.

Recognizing autistic trait in parents

My dad's more autistic than I'll ever be but he wont admit it, he doesn't see it at all

My dad cannot physically enjoy food when he is around other people

My dad's meal times has always been the one time when I had to keep quiet..I used to try not to blow my nose in front of him, if I had a cold, I would just try to hold it in.

My dad, I get on with but the more and more, the older he gets, the more rigid he gets. And unfortunately, he's one of those dad's who er, he'll show you an amazing side to himself then the rest of the time you have to remember you have to give him things to do, because he'll do them, he'll help you out in a sort of fixing way rather than telling you he can't cope with too much noise.

Advice to parents

Don't make it a major thing. It's not the most important breakthrough in the world…but for a person who's got a diagnosis it's useful but it's got to be used, I'd say its best to use it in an educational setting as the person may require this, but the key thing is you don't treat your kid any differently,   the only thing you should do is treat the person as a person. I hate the idea that you should take it into account if the person is rude because they're autistic; no, if you tell someone that they're rude because they're acting in a certain way, they will learn a different way to act. It doesn't matter if you upset ..if you bring them up to fit into society as they are, you've just got to cope with the fact that the person may not understand why, then we'll understand or ask why?

Appendix - 7 Group Table of Themes

Super-ordinate Themes	Participants contributing to theme	Sub-themes	Participants contributing to Sub-Theme	Key cross References	Examples of Indicative Quotes
Feeling Nurtured/supported	Alan Shaun Liam Tom	Help with connecting to the outside world	Shaun Tom Alan	P23; L 643 P2; L 35 (Shaun) P6; L156 (Tom) P4; L116 P8; L220 P7; L205	"They engaged me at all times. That was one thing they were worried about when I was younger, they always engaged me and I never gave anything back" (Shaun) " I could talk to them about what I was doing. They both helped me learn about the outside world. They talked to me about other people, what's going on in the news and how to be like other people" (Tom) "I think my parents helped me to learn more about myself, and helped me to become more in touch with people, more socially interactive. At times when I haven't been able to make many friends I'd ask my mum, explain to her my situation and she'd tell me what I'd need to know to be more in touch with people, what's going on y'know, I need to know more about expressions, she helps me to learn about facial expressions…, they helped me get in touch more with what's going on with people and the world because I always seemed to be in a world of my own" (Tom)

					“ I could talk to them about what I was doing. They both helped me learn about the outside world. They talked to me about other people and how to be like other people” (Alan)
		Feeling emotionally supported/contained	Shaun Tom Liam	P25;L 687(Liam)	“ She was the parent who was always there for me. Say I’d been ill, upset or I needed help with something,she’s always been the one there…..where as my dad has not always been like that” (Liam)
				P3; L91 (Tom) P6; L164	“ When I was very young I’d cuddle up to my parents, my mum, not all the time, when I was upset .People with AS are very sensitive, s there were times when we get really upset y’know, so if I started crying I’d go and cuddle up” (Tom)
				(Shaun) P16;L464 P17;L500 P17; L490	“ They gave me the right amount of attention. They taught me the rules when I was younger..they allowed me to understand that just because I’m hunting for attention, doesn’t mean I’m going to win all the time..” (Shaun) “They were rewarding in the right ay, never overboard” (Shaun)
		Viewing parents as positive role models	Shaun Alan Liam	P23; L 643 P2; L 35 (Shaun)	“ I think I take after my mum in the way I act. I followed her lead in things like work..in an understanding that being brought up by such a person has brought me up in a certain way means

			Tom		I’ve got a better view point in life” (Shaun)
				P12; L344 – 364 (Alan)	“ my parents have always been careful people. You know always makin’ sure that,.. always just checkin’ that they’re doin’ the right thing an’such, so yeah, I suppose that’s something they’ve taught me and I’ve learned from watchin’ them, yer know, just to try to….take care of who I am and how I act and so on really”, Just makin’ sure that I’m quite confident and capable of doin’ something before I go ahead and try it out really”. (Alan)
				P4; L79* (Liam)	I think it was unusually sheltered but it was a nice background, ‘cause a lot of my peers probably came from backgrounds where if they, erm, hurt somebody or did something wrong when they were little/ it’s incredible that there’s so many backgrounds where the parents wouldn’t feel responsible. My parents would, which is why I’ve grown up to be a nice person” But the great thing is you will never grow up in a background like mine that will make you so content and appreciated of thing in life. There’s too many people out there who always want more, or want better. With us it’s as long as something’s good enough then you’ve got it. (Liam)
					“ A good thing my dad did was when ever a big news story came on he would always make us watch things on

		Diagnosis facilitating change and understanding	Alan Liam Ian Tom Terry	P8, L; 221 (Tom) (Alan) P4, L121 P10,L298 (Liam) P24, L645 (Ian) P17, L497 (Tom) P6, L177	the news so we would know what's going on in the world. I didn't always appreciate it then,, I think I was a bit ignorant, but I think it was a good thing now" (Tom) "before I got diagnosed, it was always one of well…sheer confusion really, my parents didn't know really or … figure out what was up with me [ ]after I was diagnosed my parents became a lot more, like, understandin' and err…. and like realisin' of what it was like and I suppose it help them be a lot more supportive and enouragin' and, err, it made my / it made my family life a lot more secure" (Alan) "my life before hand there was always an expectancy of somethin' and if I don't give whatever it is, it's a failing. But, when I got my diagnosis, if something goes wrong, oh, it's the Asperger's or the dyspraxia or what ever I'm diagnosed with, there is actually a reason, it's not your fault. So it's kind of that effect". (Liam) " I think I got more respect from my dad, he can say I'm not being awkward, I've got Asperger's so, he can see, my, where I erm, look stressed, he can understand that where he might not have been able to before.[.].it takes the pressure off in a way"(Ian) [my parents] could understand why I kept staring at things and got so obsessive with things like tractors, and also the same with teachers at school. They're were able to tell people at

				(Terry) P35, L601	school what was going on and help them to help me . They could understand more about me and why I get so distractible and not listening to what’s going on”(Tom) I’ve felt better in that there was a reason behind things, as I say I found out that I wasn’t stupid, I was intelligent, which has led me to socialise better I think, particularly amongst very intelligent people, amongst academics. It’s also given me another interest, Mensa (Terry)
Feeling Restricted/Held Back	Shaun Liam Graham	Pressure to achieve academically	Graham Liam Ian	P6;L129 (Graham) P5; L133 *(Liam) P23, L 627* P15, L434 (Rob)	“I think their expectations were so high ..I had a high IQ and so people in the classroom expected me to do well, and I could do quite well in the classroom but when it came to exams, I kind of couldn’t put it all together. I couldn’t handle the pressure”. (Graham) “I expected them to be more supportive and just be content..I hear everyone saying there’s no hope for you unless you do this, that and the other…’ (Liam) “it still has it’s tension there, y’ know, who’s which one of the children is going to achieve the most y’know and at the moment it’s Jess, she’s / or I think Dave could go ahead cause Dave’s got the ability to design a few

		Feeling Controlled	Liam Graham	P3; Ll60 P3; Ll60 (Liam) P11; L240* P12; 266* P3;L63 P3, L 51 (Graham) P24, L531	buildings” (Ian), “my mum’s, one of the reason’s why I may live on my own when I’m older is because I’d never have to check with her, like I’m a allowed to play rugby, am I allowed to have a girlfriend, and so on or am I allowed to do this. In the past, I’d take for granted that she’d let me when I was younger but, for some reason now, she seems to, like, *no, you can’t do this, no, you can’t do that,* I’m like, you let me as a child, but you don’t let me as an adult most of the time”. (Liam) “ I think it makes me a bit apprehensive towards somebody who that I know has always and still does to a varying degree,yeah look after me, (Liam) “I just felt really controlled. I think my parents lived a really controlled life and part of their control was me and especially my mum. My dad was really anxious about things”. (Graham) “ I think my mum controlled me on almost every level..and that was really really hard” (Graham) “They were good at setting boundaries what they weren’t good at was giving / they gave me unconditional love, because I knew they always loved me but they never gave me freedom to experiment and to ..to be me, to break out and say, ‘yeah, yeah, this is who I

		Undermining a secure sense of self	Shaun	P4; L 131 P8,L225 P5; L140 P8; L225 P9; 252 (Shaun)	am'…(Graham) she was really, really emotionally and sexually repressed and controlling and I think that contributed to..I found it difficult to understand social rules and thing like that anyway, but that made me feel, even more like there was something wrong with me. (Graham) " It wasn't my choice, it was/it wasn't that I was pushed into it, it just wasn't my decision as such…..I was at a point quite comfortable with/ I wasn't standing there going 'mummy, what's up with me'(Shaun) " As far as Asperger's diagnosis, it didn't mean anything to me.It's very hard if you've already know yourself and worked yourself out" (Shaun) " I wished nothing had happened, y'know, That I was left to live my whole life without it" (Shaun) "As Far as growing as a person, I think I was quite capable of not going off the rails . I think I was at the age when I was stable and pretty sure I knew what I was doing and I knew who I was. I didn't want to destroy myself or anything" (Shaun) " I'm not one of those people who sat there and thought 'oh wow, I've got a diagnosis, it's great, go back, still

					haven’t got any friends but look my diagnosis is here!..If you grow up with something and you don’t know it, it’s ok, I would have almost preferred not to have had the diagnosis. I think it came at the wrong time. If you get it early enough you’re helped through school, if you get it later then people have a different perception of you and you don’t turn into who you are” (Shaun)
		Parents not understanding/providing what I *really* needed	Graham Terry Liam Alan Ian	P21;L473* P23, L518* (Graham) P22, L498 L307(Terry) P31; L539 (Terry) P11; 298 - 355 P17; L289	“they helped me with my dyslexia and they tried to get me into university ..But none of it was any use to me because the real life skills, that were really foundational are the abilities to actually interact and seek to actually feel that you are a human being and my parents weren’t actually able to give me that. ”. (Graham) “but my parents didn’t do anything, they didn’t do anything to help. They got me help for my dyslexia, they were terribly concerned. They did want to help……..but it was like they were so afraid” (Graham) “[I would have liked them to] help me with socializing, making friends, girlfriends…boys brigade or something” (Terry) “ I would have liked more affection, more talking, to feel wanted and helped. If I had been diagnosed earlier in junior school, not necessarily for AS for dyslexia that would have made a difference, or even if they’d have done an IQ test on me they’d have known

				P11; L(liam) P1; L32 (Ian) P2; L47 P3; L75 P6; L179 (Alan)	something was wrong" (Terry) "….I never knew what was coming around the corner, it would have been nice if somebody would have said 'before you go through puberty these changes might happen…" (Liam) "well, mum used to go to a lot of Rolling Stones concerts and she was into that whole sixties vibe you know, that whole thing and we were just kind of ignored really as kids, we didn't really have much time with mum and dad, so"… I could have done with more structure really, there were no rules" (Ian) I know they always said so but when I felt that/ so distressed they always seemed quite annoyed with me about it I mean if..they were or they weren't but they always tried to put me off tryin' to speak to 'em and er…….that's just it, I mean….although it can't be helped really, because, errr, we, me and them, and everyone else never seemed to really know what was up at that point sooo, I can't.. really argue with what happened" (Alan)
Sense of Loss	Terry Shaun Liam Graham Rob	Missed opportunities in life	Terry Shaun Liam	(Terry) P15; L247* P21, L261;	"[psychologist] once asked me what my childhood was like, I eventually came up with the word, empty, yeah, just felt to a large degree that it was all a waste of time" (Terry) " A bit of anger that I might have done a lot more with my life…I was being

				P2;L33 P37; L643*	told that this level of intelligence is what professors have at universities and things like that. I suppose there is a certain amount of anger that if I’d have been diagnosed when I was young something could have been done to educate me more” (Terry)
				P30; L847 P29;L836 (Shaun)	“There’s so many things I’d wished I could have done, y’know, just if I’d been given a chance to learn things mechanical, musical or domestic.If I’d have been given things to do when I was younger…in terms of helping me with my car, cooking or anything, I feel it’s difficult to learn now” (Shaun)
				P32; L 859 P26; L723 (Liam)	“I didn’t realize that I spent most of my life in a world of my own, which has cost me dearly. If I’d have lived more reality I probably would have achieved a hell of a lot more than what I have” (Liam)
				P16’ L521(Rob) P4; L114	“I’m constantly the one who’s tryin’ to achieve more and tryin’ to better / it’s a cleche but more is better really, so erm, it’s difficult to know erm, yeah, it’s I suppose it’s just one of those things you’ll nev/ you’ll never understand what you could have achieved until you look back afterwards y’know, so it’s just getting’ in there and being able to sit at your corner and being able to fight for your course y’know”
		Feeling Emotionally	Graham	P4;L88	“ I didn’t have much of a relationship

		/socially deprived	Terry	P29; L429 P13;L211(Terry) (twins) P17; 288 P1;L12 ; P1,L19(Graham)	with my mother. I can't remember being hugged, kissed or anything. There was not even any sort of social interaction, " (Terry) " he used to tuck me up in bed and give me a kiss goodnight up to the age of six and I CLEARLY remember the day when he said ' oh, you're too old to give a kiss to'. I was really, really hurt by that and that was the age of about six. And I can remember that now. It was absolutely horrific". (Graham) "When I was a teenager I remember when about…eighteen, no ones ever touched me for years….years and years and years. I hadn't been touched.. No one's put their hand on my shoulder or anything (Graham) " Why was it ok to have this affection up until this point? What came across was my dad's anxiety/he was basically homophobic really and what came across was like my dad wasn't comfortable kissing a boy after the age of six, it was like you're too old"(G)
Appreciation of discipline			Alan Rob Liam Shaun	(Alan) P13, L388	"my parents, were never afraid to smack me, although I think in hindsight that was a good thing, it sort of taught me to not, well, to listen to my parents really, I mean I know in now days, political correctness an' all that, it's a lot…people are a bit more afraid to, or hesitant to discipline their kids in case they get the counsel round or…/ ner

				P3, L79 (Rob)* Pp8, L266 P 3, L83(Liam)	my parents were / my parents were quite strict with me when I was younger and err, that taught me, in a sense to make sure I listened to em' (Alan) Could have done with more guidance, we just didn't have any rules or guidance y'know" (Rob) "physical control, yeah I'd say, my dad used to cuff us. I think that was fantastic, cause it set a limit for us, a clear guideline. I think kids today aren't allowed to be cuffed I think that's the difference today between Victorian children who were correct and well brought up and modern children who are just vandals running a mock, you know, urban gorillas like animals in a concrete jungle, you know, but in the past they were well behaved children, and I think the difference is a firm cuff behind the ear" It gave us a structure, it allowed us to know right from wrong really.(Rob) . It's incredible that there's so many backgrounds were the parents wouldn't feel responsible. My parents would , would be irate if I acted like that, which is why I've grown up to be a nice person, so I'm very grateful. But the great thing is you will never grow up in a background like mine that will make you so content and appreciated of thing in life. There's too many people out there who always want more, or want better. With us it's as long as something's good enough then you've got it.

				P17, L489 (Shaun)	in life you l “in life you learn and learn and learn and you learn what’s right and what’s wrong and so, my parents taught me, well, let me find out what was right and what was wrong. They told me when I was doing something wrong, not that I’m doing / I hate the idea when people tell you when you’re right and when you’re wrong. When you’re really doing something silly, erm I don’t mean (incoherent), when you’re doing something that will get you into trouble, erm then they told me off. That’s solid, that’s important (shaun)
Advice to parents			Tom Terry Graham Alan Rob Liam	P8; L227 (Tom) P40; L690 (Terry) P27, L613(G)	“ We can be sort of sensitive at times, so if you’re going to tell us off, try not to be too harsh. It’s always good to discipline them, but be sensitive if you can. Be aware that we don’t always know what’s going on a lot of the time” (Tom) “ To be open and honest and help them to socialize, like join the boy scouts or something. To get them into groups where they have to be in that group and then they will form relationships. They might not like it very much but one they’ve been there for a while, they will make friends. Also to show them affection overtly, be really hands on because if it’s done subtly the child wont recognize it, it’s got to be over the top” (Terry) “ don’t feel badly about yourself for having really negative feelings towards your own child, because that’s

					understanderble and to admit that you can’t cope with your child and you can’t relate to them and it doesn’t make any sense..if the parents relax and be themselves then they can start to face the problems in the relationship”” (G)
				P15, L432 (Alan)	“make sure you’re there for them, encourage ‘em to use their gifts, at the same time teach them, teach them what you know about how to.. act in society an’ what to say an’ so on so don’t be afraid to be there for them an’ teach ‘em an’ at the same time sort of marvel at what they know ‘cause they ……they can end up doin’ quite well in life really with the gifts they got so…Allan)
				P17, L547 (Rob)	“Don’t pressure them. Let them develop at their own pace, and erm, if there is an opening for , say a scholarship, or a grant or something, apply for it and don’t treat them specially, don’t single them out, don’t kind of segregate them, but, erm, cause essentially if one develops well the knock on benefit of that will be like a trickle down effect “ (Rob)
				P32, L860 (Liam)	, I suppose for children with Asperger’s who grow up into adults is just to make them realise that they know how they are because until this year, I didn’t realise that I spend most of my life in a world of my own, which has cost me dearly, because if lived more reality I probably would have achieved a hell of a lot more than what I already have” (Liam)

				Shaun P33, L924	Don’t make it a major thing. It’s not the most important breakthrough in the world…but for a person who’s got a diagnosis it’s useful but it’s got to be used, I’d say its best to use it in an educational setting as the person may require this, but the key thing is you don’t treat your kid any differently, the only thing you should do is treat the person as a person. I hate the idea that you should take it into account if the person is rude because they’re autistic; no, if you tell someone that they’re rude because they’re acting in a certain way, they will learn a different way to act. It doesn’t matter if you upset ..if you bring them up to fit into society as they are, you’ve just got to cope with the fact that the person may not understand why, then we’ll understand or ask why?” (Shaun).

Appendix 8 Notes to Authors for Research Paper

Autism

(available hard copy only)