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AN EXPLORATION OF PARENTAL NARRATIVES IN THE
CONTEXT OF A CHILD'S DIAGNOSIS OF AUTISM SPECTRUM
DISORDER.

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SALOMONS
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Assessment Cover Sheet (This has been removed from the electronic copy)

Declaration (This has been removed from the electronic copy)

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Summary of Portfolio

Section A

A critical review of current literature regarding the parental experiences of receiving, and making sense of, a diagnosis of an Autism Spectrum Disorder (ASD) for their child where there is no learning disability present. It begins with an overview of the current debates in the diagnosis of ASD and considers how parents make sense of a diagnosis. The review then evaluates papers pertaining to parent's experiences of receiving a diagnosis for their child, their experience of living with ASD and the efficacy of post-diagnostic psycho-education interventions. A consideration of the clinical and research implications of these findings concludes the paper.

Section B

This paper provides the findings of a narrative study examining the development of parental narratives following the diagnosis of their child with high functioning autism or Asperger's syndrome. Seven parents who were participating in a post-diagnostic psycho-education group were interviewed across two time points. The findings highlight the parents' development of a new framework enabling the creation of an alternative personal and family narrative. The implications this has on parental well-being are discussed and recommendations are made for future research to build on these initial findings.

Section C

A critical appraisal and reflective account of the study presented in section B. This includes consideration of development of research skills, limitations of the study, clinical implications, and future research ideas.

Table of Contents

List of appendices	8
Section A	9
Abstract	10
1. Introduction	11
1.1 Diagnosis of ASD	12
1.2 Utility of Diagnosis	13
1.3 Meaning Making	14
2. Review of Empirical Literature	16
2.1 Rationale for review	16
2.2 Review structure	17
2.3 Methods and search strategy	17
3. Literature Review	18
3.1 Receiving a diagnosis	18
3.2 Living with ASD	22
3.3 Post-diagnostic Interventions	27
4. Future Research	29
5. References	31
Section B	45
Abstract	46
Introduction	47
Method	51
Results	56
Discussion	71
Conclusion	77
References	78

Section C	86
Question 1	87
Question 2	88
Question 3	90
Question 4	91
References	93
Appendices	96

List of Appendices

Appendix A: Literature review search strategy	97
Appendix B: NHS Ethics approval letter	99
Appendix C: Research and Development approval letter	102
Appendix D: PEGASUS Protocol	103
Appendix E: Interview Frame	112
Appendix F: Parental Information Sheet	114
Appendix G: Parental Consent Form	118
Appendix H: Research Diary	119
Appendix I: Interview Transcript, Interview 2	123
Appendix J: Overall Narrative Analysis, Interview 2	128
Appendix K: Summary Narrative, Interview 2	134
Appendix L: Grand Narratives	135
Appendix M: End of Study Letter and Report	137
Appendix N: Submission Guidelines for Journal	141

SECTION A

Section A: The impact of a child's diagnosis of Autism Spectrum Disorder on parents

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Abstract

This review explores the current literature regarding the parental experiences of receiving, and making sense of, a diagnosis of an Autism Spectrum Disorder (ASD) for their child where there is no learning disability present. It begins with a brief overview of the current debates in the diagnosis of ASD and considers how parents make sense of a diagnosis. The review then evaluates 16 papers pertaining to parents' experiences of receiving a diagnosis of ASD for their child, 17 papers on living with ASD, and 7 papers on post-diagnostic psycho-education interventions. The literature reviewed confirmed that receiving a diagnosis of ASD for a child is a highly significant event, arousing a range of responses in parents. However, there remains uncertainty as to the factors that contribute to the wide variability in parents' reactions due to a paucity of evidence. The findings of this review also suggest that psycho-educational interventions enable parents to better understand the ASD diagnosis, develop self-confidence and self-esteem, and change the way they perceive their child's behaviour. A consideration of the clinical and research implications of these findings concludes the paper.

1. Introduction

Autism Spectrum Disorders (ASD) are a heterogeneous group of diagnoses, characterised by a triad of impairments; social interaction, communication and repetitive and stereotyped behaviours (American Psychiatric Association (APA), 2000). Whilst prevalence rates of ASD can vary dependent on diagnostic criteria utilised, age of sample and location of study (Williams, Higgins & Brayne, 2006), there is a general consensus of a 1% prevalence rate in the United Kingdom (UK) (Baird et al., 2006; Baron-Cohen et al., 2009; Scott, Baron-Cohen, Bolton & Brayne, 2002).

Regardless of severity, ASD is a lifelong pervasive developmental disorder (PDD) that significantly impacts upon the individual and their family (National Institute for Health and Clinical Excellence (NICE), 2011a). The trajectory of ASD varies tremendously and is largely dependent on variables of IQ and language (Charman, 2008). This heterogeneity is often a source of uncertainty for parents and is thought to contribute to a lack of understanding of ASD within society (National Autistic Society (NAS), 2007).

Mental health difficulties are highly prevalent, often occurring in multiples in young people with ASD (Simonoff et al., 2008). Research examining quality of life of children with ASD highlights that the positive elements of the child's life come almost exclusively from the family environment. This places significant demand on the parents as they provide support for their child and work to develop positive interactions between the child and the wider environment (Schormans, Renwick, Ryan & Lim, 2005).

Definitive criteria have evolved within the context of a developing understanding of the aetiology of ASD. When 'early infantile autism' was initially described in 1943 the child's behaviours were understood, under a psychoanalytic framework, as a disorder of emotional development (Bettelheim, 1967; Kanner, 1943). Over time, psychoanalytic theories of ASD were refuted and replaced by biological and cognitive theories (Rutter, 1968). There

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

have been substantial developments within neurobiological and neuropsychological research but a biological marker of ASD remains undiscovered (Rutter, 2011). The genetic heritability of ASD is however widely accepted within the field with twin studies consistently showing a heritability rate of 90% (Bailey et al., 1995). With limited progress in identifying a clear cause or treatment for ASD and the growth of recognition of ASD in young people with no generalised learning disability (Myles & Simpson, 2002), voices from both realist and social constructionist positions are increasingly questioning the exclusive use of the medical model to understand ASD (Nadesan, 2005). It is suggested that a social model promoting the embracing of difference and adaptation of the environment may be a more positive way of framing ASD (Molloy & Vasil, 2002). In keeping with this, psycho-education has become the most prominent intervention in clinical practice (NICE, 2011b).

This paper will provide a brief overview of the current debates in the diagnosis of ASD and consider how parents make sense of a diagnosis. Due to the added complexity of a dual diagnosis of ASD and learning disability, this review focuses particularly on the diagnosis of ASD without a generalised learning disability. Following this introduction a detailed review of the empirical literature relating to parents' experiences of receiving a diagnosis for, and living with, a child with ASD and the psycho-educational interventions available for parents will be summarised and critiqued. A consideration of the clinical and research implications of the literature will conclude the paper.

1.1 Diagnosis of ASD

Clinical guidance recommends that diagnosis of ASD should only be given following a multifaceted assessment that utilises more than one assessment tool (NICE, 2011a). There are two diagnostic criteria that may be employed in the assessment of ASD; the Diagnostic and Statistical Manual (DSM-IV-TR) (APA, 2000) and the International Classification of

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

Diseases (ICD-10) (World Health Organisation (WHO), 1993). Whilst the diagnostic criteria slightly differ, both classification systems place autism, Asperger's Syndrome (AS) and PDD – Not Otherwise Specified (PDD-NOS) under the umbrella category of PDD. A range of diagnostic labels appear in the literature including High Functioning Autism (HFA). In keeping with NICE guidelines this report will use the term Autism Spectrum Disorders (ASD) as an umbrella term for these diagnoses, and for the purposes of this thesis ASD without learning disabilities is equivalent to HFA and AS.

Research has demonstrated that it is possible to diagnose autism in children under the age of three years in the context of a genetic disorder, language disorder, or generalised learning disability (Cox et al., 1999; Moore & Goodson, 2003). The average age of diagnosis of autism outside these contexts is approximately five years however, the mean age of diagnoses of HFA or AS is 11 years (Cederlund & Gillberg, 2004; Howlin & Asgharian, 1999). This later diagnosis means that parents have spent many years struggling to understand their child and often end up questioning their own abilities as parents (Sofronoff & Farbotko, 2002).

1.2 Utility of Diagnosis

Clinical diagnoses should have both diagnostic validity (where the diagnosis is a valid construct) and clinical utility (communication of clinically relevant information) (First et al., 2004). The ever evolving construct of ASD has led to challenges regarding the concept of ASD (Happé, Ronald & Plomin, 2006), which arguably casts doubt on its validity and utility.

Studies examining differences between autism and AS, controlling for IQ, have found little evidence of significant difference in the aetiology of the symptoms, outcomes or prognosis (Witwer & Lecavalier, 2008). The diagnosis of PDD-NOS has been demonstrated to be the most unreliable of all ASD subtypes (Mandy, Charman, Gilmour & Skuse, 2011).

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

Many of the difficulties encountered with exploring validity of ASD are hypothesised to occur due to a lack of specificity, use of different diagnostic criteria and a lack of homogeneity in samples (Volkmar & Klin, 2000). The upcoming publication of DSM-V proposes to re-classify the current sub-types into one heterogeneous spectrum group called 'Autism Spectrum Disorder' located under a category of 'Neurodevelopmental Disorders' (APA, 2011). It is hoped that this change will increase the reliability and validity of ASD (Lord & Jones, 2012), although others contest the usefulness of this change (Singh, 2011).

Research has demonstrated the lack of reliability in differentiating between ASD sub-types, despite fidelity to validated standardised assessment tools (Lord et al., 2012). However, the development of a profile of strengths and weaknesses during assessment is helpful in informing clinicians about a child's prognosis and determining appropriate interventions (Francis, 2005; Seida et al., 2009).

Giving a diagnosis of ASD is part of a wider debate regarding the usefulness and relevance of diagnoses and whether it is right to give children a label based on deficits (Molloy & Vasil, 2002). Research and service user literature exploring the opinions of those given the diagnosis and their families has mixed findings; some feel that the diagnosis helps to make sense of their lives whilst others find it an unhelpful label with negative connotations (Cohen-Rottenberg, 2009; Huws & Jones, 2008; Ruiz Calzada, Pistrang & Mandy, 2011).

1.3 Meaning Making

In the early models of response to a significant event, it was believed that people moved sequentially through stages of emotional response before moving into a place of reorganisation (Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975). Stage models are now widely contested as it is acknowledged that adjustment is a highly individual process

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

influenced by factors such as the characteristics of family members, patterns of family interaction and ability to manage stress (Gargiulo & Kilgo, 2011).

One of the leading models of understanding how parents make sense of an event such as diagnosis is the Family Adjustment and Adaptation Response Model (FAAR) (Patterson, 1988). This process model comprises the modes of adjustment and adaptation and is derived from the Double ABCX model of family behaviour (McCubbin & Patterson, 1983). The Double ABCX model proposes that the interaction between severity of the event, demands already imposed on the family, family resources, interpretation of the event and coping strategies determines the level of stress experienced. The FAAR model postulates that the aim of the family is to maintain balance and functioning through both adjustment and adaptation. In adjustment, families are relatively stable and draw upon pre-existing resources. Following a crisis, the family must adapt by acquiring resources, developing new coping strategies, reducing demand, and considering the meaning that they give to the crisis.

A central component to these models is the meaning the family gives to an event. Indeed the central component of cognitive models of adaptation is that it is the interpretations made about an event that determine the response of the individual (Lazarus & Folkman, 1982). A theory of cognitive adaptation was proposed by Taylor (1983) who identified three components to an individual's process of adjustment; a search for meaning, regaining control and increased self-esteem.

Making sense of events is a core element of narrative therapy: it is seen as an essential task in being able to make sense of one's life (White & Epston, 1990). Models of the family life cycle suggest that a family needs to be able to adapt and negotiate through tasks that present throughout family life but particularly at points of transition. In families of children with ASD the task of meeting these transitional milestones is often disrupted (Stoddart, 2005a). The way in which families negotiate these tasks, and form a coherent narrative, will

be based on the beliefs that are held as individuals, a family and in relation to wider society (Dallos & Draper, 2010).

2. Review of Empirical Literature

2.1 Rationale for review

Having a child with a diagnosis of ASD in the family has a significant impact on the child, immediate and wider family. Service user literature, produced by parents, describes a process of adaptation to the diagnosis that is often not supported by services (NAS, 2010). Research in fields such as clinical health and learning disabilities has explored parents' adjustment to diagnosis and disability. Hypothetical models of this process have been used to inform diagnostic processes and post-diagnostic support (e.g. de Ridder, Geenen, Kuijer & van Middendorp, 2008; Yau & Li-Tsang, 1999).

Receiving a diagnosis can challenge a parent's belief system about themselves as a parent, their child with the diagnosis, and their family as a whole (Thompson & Janigian, 1988). Whilst psycho-educational interventions are increasingly being delivered for parents, there is a paucity of research aimed at understanding individuals' process of meaning making following their child being given a diagnosis of ASD without LD (Blacher, Kraemer & Schalow, 2003).

Parenting a child with ASD where there is no learning disability present holds very different challenges as compared to parenting a child with a dual diagnosis of ASD and learning disability. Often the subtlety of the presentation of difficulties in higher functioning children causes greater difficulty in gaining clear understanding of the difficulties resulting in delayed diagnoses and there is less understanding of the condition within wider society, all of which have a significant impact on both the child and their family (Stoddart, 2005b). Due to the earlier age of receiving a diagnosis, parents of children with ASD and learning disabilities often have access to a wider range of support services as a result of the initiative of the

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

National Autism Plan (NIASA, 2003). Programmes such as the NAS Early Bird Programme (Shields, 2001) and early interventions (Howlin, Magiati & Charman, 2009) are also widely accessible. Comparatively, there is a paucity of formal support available for parents of children with ASD without a learning disability (Stoddart, 2005a).

This review therefore explores the current literature regarding the parental experiences of receiving, and making sense of, a diagnosis of ASD for their child where there is no learning disability present.

2.2 Review structure

The review contains three sections that summarise and critique the literature examining: parental experiences of receiving a diagnosis for their child, their experience of living with ASD and the efficacy of post-diagnostic psycho-education interventions for parents.

2.3 Methods and search strategy

Relevant literature was identified through electronic searches of the following databases: SAGE Journals, Web of Knowledge, ScienceDirect, and PsychINFO. Further papers were identified via: NHS Evidence, Google, Google Scholar, and a manual search of reference lists and citations of papers. The full protocol for the search is located in appendix A.

In total 16 papers were identified pertaining to receiving a diagnosis, 17 papers on living with ASD, and 7 papers on post-diagnostic psycho-education interventions.

3. Literature Review

3.1 Receiving a diagnosis

Research has examined the journey that parents travel in getting a diagnosis for their child and their experiences of services during this time.

Raising awareness of difficulties

In one of the largest UK wide surveys in ASD, the responses of 1295 parents of children with ASD highlighted the difficulties that parents can experience in getting an understanding of their child's difficulties. Once parents had received a referral from their GP to specialist services, 68% required three or more autism specific assessments prior to diagnosis being given (Howlin & Moorf, 1997). A subsequent study of the sample demonstrated that diagnosis of AS required assessments with a greater number of professionals as compared to children diagnosed with autism (Howlin & Asgharian, 1999). Despite advances in assessment, a questionnaire study of 960 parents in America by Mandell, et al. (2005) found the same disparity in time taken to receive a diagnosis. However, this study identified Social Economic Status as a variable contributing to the delay. Given the healthcare system in America, it is possible that finances affected the assessment process. In a survey of 56 parents in Canada (Siklos & Kerns, 2007), the child's age at diagnosis significantly correlated with a greater delay. It also identified that females took longer to receive a diagnosis as compared to males. This suggests that the more complex the presentation, the less secure professionals may feel in making a diagnosis.

This delay arises as a theme of a 'fight' within qualitative studies. Braiden, Bothwell and Duffy (2010) completed semi-structured interviews with 11 mothers of children with ASD in Ireland. This highlighted the theme of a 'fight' to get concerns heard by health professionals and to navigate the complex assessment process. Rajkovic, Thompson, and

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

Valentine (2010) reported similar themes in a qualitative study completed in Australia with 32 parents. Here, parents reported feeling that they had to ‘fight the system’ in order not to be ignored by professionals. In both studies, parents described the experience of assessment as ‘overwhelming’ with little support before or after the diagnostic assessment.

Without diagnosis, parents are often uncertain as to why the difficulties are occurring; this feeling is often exacerbated when there is a delay in diagnosis. In a study examining four families’ experiences of the diagnostic process, using grounded theory methodology, a theme of confusion emerged. This was seen to be associated with feelings of guilt and self-blame which could not be alleviated by family or friends and often led to social isolation (Midence & O’Neill, 1999). Uncertainty was also a theme found in a study of 11 parents using discourse analysis. Here, it was associated with parents holding multiple, often conflicting, meanings behind their child’s difficulties. This resulted in fears of not being a ‘good-enough’ parent and a dismissal of their parental abilities (Avdi, Griffin & Brough, 2000).

This research demonstrates the assumptions of narrative theory, that without a clear narrative there is risk of increased helplessness, reduced optimism and ability to problem solve (White & Epston, 1990).

Receiving the diagnosis

Being told that your child fulfils criteria for diagnosis of ASD is never an easy conversation for parents or professionals (NICE, 2011a).

The results of a study, that explored the presence of post-traumatic stress symptoms related to the event of receiving a diagnosis of ASD for a child clearly demonstrates these difficulties. In this survey of 265 parents, 20% met criteria for the event being a significant traumatic experience. Parents were more likely to experience it as traumatic if they were a single parent or if they already had a child diagnosed with ASD (Casey et al., 2012). This

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

finding mirrors the hypothesis of the Double ABCX model, as the already reduced personal resources would interact with the interpretation of the event and level of stress experienced.

Research has also focused on parents' satisfaction with assessment services.

Evaluations of services in Ireland and Scotland indicate that the majority of parents are satisfied with how a diagnosis is given. Satisfaction was associated with the provision of definitive information and having sufficient space for discussion (Brogan & Knussen, 2003). However, a large amount of the variance remained unexplained indicating that the measures used did not sufficiently capture the parental experience. One hypothesis is that response to a diagnosis is such a highly individual process parents require different types of support at different times. This is potentially reflected in the findings of Braiden et al. (2010) who found that some parents were happy with the quantity of information provided at the point of diagnosis whilst others felt overwhelmed.

In a quantitative survey of 95 parents across Ireland and Northern Ireland, 59% reported that information provided at the point of diagnosis was unclear (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). Receiving clear information was also a factor associated with satisfaction in a survey of 248 parents of children with ASD in France. Of those parents receiving diagnoses between 1990 and 2005, 63% were dissatisfied with the service due to the professional's reluctance to give a diagnosis. The authors felt that this was associated with professionals' training which continues to be heavily influenced by psychoanalytic thinking (Chamak, Bonniau, Oudaya & Ehrenberg, 2011).

Despite the use of idiosyncratic measures, these studies reflect the importance families place on clarity and information. According to narrative theory, having a clear understanding of the child's difficulties and strengths is likely to enable parents to make sense of their own lives and improve their feelings of control and self-esteem.

Reactions to the diagnosis

Studies have begun to explore the wide range of thoughts and experiences that parents experience immediately after hearing about the diagnosis.

Mansell and Morris (2004) surveyed 55 parents on their reactions to their child being given a diagnosis. The results demonstrate a turbulent process; 85% reported feeling relief and understanding, 74% felt they were able to adapt family life appropriately, 73% reported feeling more concerned about their child's future, and 68% were concerned about the assumptions and reactions of others. It has been suggested that the intangible nature of a hidden disability can make it harder for parents and others to understand the diagnosis of ASD (Midence & O'Neill, 1999).

Similarly, in a study using naturalistic enquiry, the 17 parents interviewed about their experiences of receiving a diagnosis reported feeling a wide range of emotions. These included anger, sadness and helplessness as well as relief and a sense of hope. It was noted by the authors that the response varied according to whether parents were shocked by the diagnosis (Nissenbaum, Tollefson & Reese, 2002).

The results of an internet-based study of 417 parents in America found that being shocked or surprised influenced parents choice over the type of information they wished to receive at the point of diagnosis. Those who were not surprised wanted more information concerning the aetiology of ASD. Those who were surprised were more concerned about taking practical steps such as identifying appropriate educational services (Gaspar de Alba & Bodfish, 2011).

Age of child at diagnosis was found to be a further factor influencing parental responses in a study completed by Osborne and Reed (2008) who completed 15 focus groups with 70 parents. The majority of parents with children diagnosed when younger felt that the diagnosis was unexpected, found the process unhelpful, and wanted immediate information

about ASD. Those with children diagnosed when older were more likely to report feelings of relief and wanted information and support provided over a longer period.

If an event is felt as a shock due to it being unexpected, it is likely to have greater impact and be experienced as more severe. According to the FAAR model, this is likely to increase parental stress and reduce their ability to move to a position of adaptation.

3.2 Living with ASD

There is a strong evidence base highlighting the stressful experience of raising a child with ASD, regardless of level of severity. Parents are likely to draw on a variety of coping strategies as they move to a place of adjustment.

Mental well-being

Brobst, et al. (2009) compared 25 couples with children with ASD and 20 couples with typically developing (TD) children. Parents of children with ASD reported greater stress, lower relationship satisfaction, and lower social support. Increased stress positively correlated with the perception, rather than the quantifiable number, of the child's behavioural difficulties. Similarly, Epstein, Saltzman-Benaiah, O'Hare, Goll, and Tuck (2008) identified significantly elevated levels of stress in 39 parents of children with AS. Analysis highlighted that in mothers, but not fathers, perception of the child's behaviours positively correlated with level of parenting stress.

Shur-Fen Gau et al. (2012) compared 151 parents of ASD children with 113 parents of TD children and found that parents of children with ASD reported an elevated number of family functioning problems than the comparison group. Again, mothers reported greater difficulties than fathers did.

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

The increased stress and family difficulties seen in families with ASD children have an impact on the emotional well-being of parents. Montes and Halterman (2007) screened 364 parents of children with ASD. Despite only using a sample of questions from standardised measures, they found that parents reported significant difficulties with emotional well-being, even after adjustment for the child's level of social skills. Bromley, Hare, Davison, and Emerson (2004) reported similar findings of the presence of mental health difficulties when interviewing 71 parents with standardised screening measures. The authors also found that decreased emotional well-being was associated with decreased social support.

Society and stigma

Level of stress is not simply associated with more severe behaviours in the child. One factor that affects stress is that of social support which emerges in quantitative and qualitative research. Increased stress correlated with a lack of social support in studies utilising measures of both objective and subjective perception (Brobst et al., 2009; Bromley et al., 2004; Sivberg, 2002). In qualitative interviews, parents attribute this lack of social support to a lack of formal support services and negative responses received from others.

Lutz et al. (2011) completed narrative interviews with 16 mothers of children with ASD and themes of relationship strain and support arose from the data. These themes highlighted that for some parents, social isolation, occurring due to the lack of recognition of the diagnosis by family members and friends, exacerbated stress. The mothers attributed this lack of understanding to wider societal beliefs that children's behaviour is a direct result of parenting. This theme of parental blame was also found by Farrugia (2009) who completed semi-structured interviews with 16 parents of children with ASD living in Australia. Discourse analysis highlighted a theme of enacted stigma where many parents reported losing approximately half their friendship circle due to their child's difficulties. Parents felt that the

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

stigma occurred due to their receiving blame for their child's behaviours because of a lack understanding of the meaning of the diagnosis.

Conversely, in a written questionnaire survey of 80 parents completed by Phelps et al. (2009), whilst some reported similar experiences to the above of social isolation, others reported that having a child with ASD helped them to meet other families in the same situation.

Coping with difficulties

Luther, Canham, and Cureton (2005) explored 18 families' perceptions of support and found differences in how families perceived stressful events and situations. Some families re-framed events in positive ways to avoid becoming discouraged, while others used passive appraisal that is, using passive or inactive solutions such as avoidance. The use of the latter strategy indicates that parents may feel that situations can be hopeless. A study examining coping mechanisms in 113 mothers with children with ASD identified that avoidant coping strategies correlated with depression and anger. Cognitive reframing, not the severity of the child's difficulties, were associated with maternal well-being (Benson, 2010).

It is not possible to determine direction of causality from these studies. However, according to the FAAR model, without the ability to develop coping strategies and reduce stress, parents will be unable to move to a position of adaptation.

Spirituality has been reported as a source of support and a coping mechanism for some parents of children with ASD (Lutz et al., 2011). In one survey, 83% of the sample spoke of faith as helping to provide a frame through which to understand why they have a child with ASD (Luther et al., 2005). Spirituality was also a theme found in a grounded theory analysis of activity on an email discussion forum. Parents describe a belief that a child with ASD is a gift from God and represents their having a higher purpose (Huws, Jones &

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

Ingledeu, 2001). Parents also describe being thankful to God for the experience that they have been given (Phelps et al., 2009).

These studies highlight the importance, as described in narrative theories, of finding meaning in an event. They demonstrate the positive impact this appears to have on one's sense of self and wellbeing.

The process of adjustment

Cognitive reframing also appears to be a key aspect of enabling parents to adjust to having the diagnosis of ASD in their lives. Reframing difficult behaviours as being a part of the presentation of ASD seems to help parents understand why they are occurring. However, as the study by Huws, et al. (2001) identifies, the differing perceptions of 'normal' can result in a complex stalemate. Parents want society to accept their child, but this results in the child being judged by the societal expectations of normal behaviour. In line with narrative ideas, the process of adjustment therefore also requires parents to find their own position within these paradoxes to enable them to create coherence in their family and personal narratives.

A narrative study of the content of 20 personal websites of parents with children with ASD highlighted a central theme of striving to increase knowledge of the condition in order to empower themselves to provide for their child (Fleischmann, 2004). The same theme was also identified in an grounded theory analysis of 33 personal websites (Fleischmann, 2005). Whilst this theme is reflected in a range of service user literature (e.g. Henley & Henley, 2011; Rodman, 2003) it must be recognised that these stories are representative of those who choose to publish their experiences and therefore may not be a representative sample of all parents of children with ASD.

In semi-structured interviews with eight parents of children with ASD, difficult events were also seen to be reframed as opportunities for learning (King, Baxter, Rosenbaum,

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

Zwaigenbaum & Bates, 2009). The design of the study enabled a comparison of beliefs in parents of children at key transition points. This uncovered differences in beliefs at different time points where the perception of the child's individuality, initially understood as symptoms of ASD, become a source of inspiration and learning.

This provides evidence of the constant movement between adjustment and adaptation hypothesised by the FAAR model.

A non-linear model of the process of adjustment has been constructed using narratives from 16 families (Lutz et al., 2011). The story begins at diagnosis and the parent moves from a position of focus on seeking answers through to a redefined positioning of hopes for the future. One hypothesis could be that the parents' story develops as it is re-authored through experience and knowledge.

The limited literature suggests that parents' narratives and meanings change over time. However, no study controlled for how long the parents had been aware of the diagnosis and therefore no firm conclusions may be drawn about the directionality of change.

Positive experiences

It is important to acknowledge that many of the studies reviewed also highlight parents' positive experiences of raising a child with ASD. Parents described learning to view the world from a different perspective (Fleischmann, 2004, 2005; Lutz et al., 2011). Families can have both 'good days' and 'bad days'; not everyday may be difficult and occasionally things can feel 'normal' (Hutton & Caron, 2005; Huws et al., 2001).

3.3 Post-diagnostic Interventions

Comparative to findings of recent reviews (Pillay, Alderson-Day, Wright, Williams & Urwin, 2011), the review of literature in this area revealed a paucity of studies empirically examining the impact of psycho-education for parents of children with ASD without global developmental delay.

Mulligan, Steel, MacCulloch and Nicholas (2010) asked focus groups, totalling 13 participants, to review an information book about ASD, created by a service. Participants reported it to be a useful source of information and felt it offered hope to parents. They considered this provision of hope particularly important as it offset an assessment experienced as deficit-focused. Self-help materials are becoming an increasingly important intervention source within mental health services. However, this study used a sample of parents who were at least two years post diagnosis and were therefore not the intended target audience.

Outcome data collected over a period of four years from a psycho-education group for parents of children with ASD aged between 4 and 18 years indicated that parents developed an increased understanding of ASD, increased confidence and hope for the future (Pillay et al., 2011). Parents' perception of their child's difficulties inversely correlated with their knowledge and confidence. A similar service evaluation of a pilot of a problem solving and support group for eight parents identified that they particularly valued the opportunity to meet other parents and learn from each other (Elsworth, Chowdhury & Arthur, 2003). Roberts and Pickering (2010) evaluated an adaptation of Incredible Years Program, a manualised parenting program originally constructed as an intervention for parents of children with conduct disorder (NICE, 2006). Parents felt that the support of the group was highly valuable and outcome measures demonstrated an increase in parental well-being and a decrease of difficult behaviours.

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

None of these studies completed follow-up measures and as such it is unclear whether the changes identified lasted over time. With a lack of control group, it is also unclear whether the changes noted in the parents may have occurred naturally over time as parents adjusted to the diagnosis.

A psycho-education program with a problem solving component was delivered to 10 families over two groups using a waitlist control design (Solomon, Goodlin-Jones & Anders, 2004). Results from this study identified non-significant but directional decreases in depression and slight increases in confidence in the intervention group as compared to the waitlist control group. Within the intervention groups, results demonstrated a negative correlation between parent's perception of problems and satisfaction in their parenting abilities.

There has only been one randomised controlled trial (RCT) completed that examined the benefits of a manualised psycho-education intervention. Parents were randomly allocated to either a one day workshop (n=33), six individual sessions (n=36) or non-intervention control group (n=20). Mothers reported an increase in self-efficacy; fathers reported no change. A non-significant decrease in self-efficacy over time was observed to occur in the control group (Sofronoff & Farbotko, 2002).

In all the studies of psycho-educational groups, parents reported an increase in mental well-being. Due to a lack of controlled trials, it is not possible to identify causality of this change. However, in keeping with narrative theories, the opportunity to gain knowledge and develop the parental and family narrative may have a role in positively influencing parental well-being and aiding the process of adjustment.

4. Future Research

The current review has confirmed that receiving a diagnosis of ASD for a child is highly significant and arouses a range of responses in parents. However, it has also demonstrated that there remains uncertainty as to the factors that contribute to the wide variability in parents' reactions.

It is possible that methodological issues account for some of this variation. The majority of the studies did not confirm the ASD diagnosis. Given the heterogeneity of the condition, and the high likelihood of unreported co-existing mental health difficulties, there is likely to have been variation in the presentations of the children. As such, a number of unknown confounding variables may have influenced outcomes. Many of the studies required parents to self-select into participation resulting in a potential sampling bias. This included internet-only studies, which limits verification of information. None of the studies reviewed considered the variable of culture. It will be important to understand how cultural beliefs, and their interaction with parental narratives, influence parents responses to a diagnosis. Given the heritability of ASD, it is possible that some parents also fulfilled criteria for diagnosis. However, none of the studies considered the implications of this. Elements of ASD are likely to impact on coping strategies and their ability to engage in interventions.

Other potential factors arise from variables identified in the outcomes of the studies. These include: age of the child at diagnosis, gender of the child, and gender of parent. All these factors may affect the diagnostic process and interact with societal beliefs about behavioural norms. Further research is required to understand the impact of these variables.

The process that parents go through following diagnosis of their child appears to vary according to their coping strategies, personal and family beliefs and overall well-being. These factors appear to alter over time, influenced by experiences, information, and support. The

SECTION A: THE IMPACT OF A DIAGNOSIS OF AN AUTISM SPECTRUM DISORDER

evidence suggests that parents move to a point where they are able to integrate information about the diagnosis into coherent personal and family narratives.

Despite the paucity of research examining the effects of psycho-education interventions for parents, the findings of this review suggest that the interventions enable parents to better understand the diagnosis, develop self-confidence and self-esteem, and change the way they perceive their child's behaviour. However, the measures used in these studies fail to identify the factors that enabled these changes to occur. To date, there has been no research using qualitative methods with parents who participate in psycho-educational interventions; this methodology may be able to capture the process of the change identified in quantitative studies.

The gathering of new information, development of understanding of behaviours and clarity over a child's weaknesses and strengths are all likely to enable parents to assimilate the new information into a coherent narrative. It seems important to understand the role that psycho-education may play in enabling parents to develop new narratives in order to fulfil the call to develop appropriate post-diagnostic support services for parents.

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SECTION B

Section B: The development of parental narratives following
diagnosis of a child with an Autism Spectrum Disorder

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Abstract

The process of adjustment in parents whose child receives a diagnosis of high functioning autism or Asperger's syndrome has been an area long neglected by research. As such, there is little understanding of the process of narrative development and parents describe a significant lack of adequate post-diagnostic support. This study is the first to examine narrative development in parents of children with high functioning autism and Asperger's syndrome. Seven parents who were participating in a psycho-education group were interviewed across two time points. Narrative analysis identified two themes that remained consistent across the time period; 'struggles and striving' and 'society and culture'. Four themes developed over time; 'self-belief', 'understanding', 'coping strategies', and 'optimism'. The findings highlight the parents' development of a new framework enabling the creation of an alternative personal and family narrative. The implications this has on parental well-being are discussed and recommendations are made for future research to build on these initial findings.

Introduction

Research has demonstrated that children with High Functioning Autism (HFA) or Asperger's Syndrome (AS) are often diagnosed much later in their life, at approximately 11 years, as compared to children with autism (Cederlund & Gillberg, 2004; Howlin & Asgharian, 1999; Mandell et al., 2005). Parents of children with HFA or AS report spending years 'fighting' with medical professionals to gain an understanding of their child's difficulties (Braiden et al., 2010; Rajkovic et al., 2010). Often, this delay leads to parents questioning their abilities or feeling guilty that they may have caused their child's difficulties (Avdi et al., 2000; Midence & O'Neill, 1999; Sofronoff & Farbotko, 2002). As such, parenting a child with ASD where there is no learning disability present brings unique challenges and difficulties as compared to parenting a child with a dual diagnosis of ASD and learning disability (Stoddart, 2005b).

Parents of children with HFA or AS, particularly mothers, are more likely to experience increased levels of stress, relationship difficulties and mental health difficulties as compared to parents of typically developing children (Brobst et al., 2009; Bromley et al., 2004; Epstein et al., 2008; Montes & Halterman, 2007; Shur-Fen Gau et al., 2012). They also report decreased levels of social support (Brobst et al., 2009; Bromley et al., 2004; Sivberg, 2002). Parents have often attributed this to a lack of support services and the negative responses received from others (Farrugia, 2009; Lutz et al., 2011).

Responses to a diagnosis

Parents experience a vast range of emotions following their child being diagnosed with an Autism Spectrum Disorder (ASD) (Mansell & Morris, 2004; Nissenbaum et al., 2002). However, parents who have children diagnosed when older, such as those with HFA or

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

AS, are more likely to experience feelings of relief from gaining an understanding of their child's difficulties (Osborne & Reed, 2008).

Stress response models are widely considered a helpful way of conceptualising responses to the diagnosis of illness or disability. These models promote factors such as resilience, and recognise that adjustment occurs in the context of a family developmental lifespan (Power & Dell Orto, 2004). The Family Adjustment and Adaptation Response Model (FAAR) incorporates the constant movement between modes of adjustment and adaptation (Patterson, 1988). When a crisis or significant event occurs, families must return from adaptation to the stable mode of adjustment by acquiring new resources, developing new strategies and considering the meaning they attribute to the event.

These models have not been explored for reliability or validity in the context of HFA or AS. However, literature examining the responses of parents to the diagnosis of their child with HFA or AS identifies a theme of striving to gain knowledge to empower themselves (Cohen-Rottenberg, 2009; Fleischmann, 2004, 2005; Henley & Henley, 2011; Rodman, 2003).

Lutz et al. (2011) have proposed a model of the process of adjustment for mothers following the diagnosis of their child with ASD. The process included the use of coping strategies of seeking answers and finding support. It also required a redefinition of roles to include new responsibilities of advocate and educator and a revision of hopes to reflect the strengths and weaknesses of their child. Again, this model has not been examined solely with parents of children with HFA or AS. Indeed, there is very limited research on the process of parental adjustment in this context.

Making meaning from a diagnosis

The meaning that the individual or family attributes to an event is seen as a core element of all adjustment models (Patterson & Garwick, 1998). Narrative therapy postulates that we naturally strive to make sense of events that occur in our lives through the creation of personal narratives (Morgan, 2000). Through the development of a coherent narrative, an individual can make sense of events and feel confident to resolve difficulties they may encounter (Sensky & Eggeling, 2010).

Parents' search for meaning about their child's behaviours is observed in the efforts they undertake to get a diagnosis for their child, their responses to it and their striving to understand behaviours in the new context. As there is currently no established aetiology of ASD, even after diagnosis, it can be difficult for parents to understand why their child has the condition and so parents often attempt to find their own explanations (Huws et al., 2001). Many parents speak of using faith and spirituality as a framework to understand why their child has ASD (Luther et al., 2005; Phelps et al., 2009). The fact that HFA and AS are non-visible disabilities makes it harder for parents and others to understand the diagnosis (Midence & O'Neill, 1999).

Narrative therapy suggests that contradictions to our personal narratives, such as the presence of ASD in the family, stretch an individuals' meaning making resources. Without a frame that provides context to experiences, they cannot be made meaningful (White, 1995). A lack of meaningful framework often results in individuals feeling helpless, less optimistic and having less problem solving abilities (White & Epston, 1990). By increasing knowledge and understanding through exploration and reflection, alternative narratives can be created, which provides a new framework through which to interpret events and attribute meaning (Gallo, 2010; Morgan, 2000).

Supporting adjustment

There is currently little post-diagnostic support (NAS, 2010) which results in parents struggling to negotiate the process of adjustment by themselves (Huws et al., 2001). In clinical health psychology, psycho-education is seen as the primary intervention in supporting adjustment following the diagnosis of illness or disability in a child (Spinks, 2009). Psycho-educational interventions aim to empower individuals through the provision of information and the sharing of ideas (Lukens & McFarlane, 2004).

There is currently a lack of empirical studies examining the efficacy of psycho-education interventions for parents of children with HFA and AS (Pillay et al., 2011). However, uncontrolled evaluation studies have demonstrated that parents report increased confidence (Pillay et al., 2011), self-efficacy (Sloman & Leef, 2005; Sofronoff & Farbotko, 2002) and psychological well-being (Roberts & Pickering, 2010).

Due to the lack of detailed evidence, it remains unclear as to how parents of children with HFA and AS evolve their narratives following diagnosis and the role they may attribute to psycho-education in this evolution. The present study sought to examine the narratives of parents of children with HFA and AS within the context of their participation in a psycho-education group. The author hoped that the present study would add to current knowledge by illuminating the process of parental meaning-making of a diagnosis of HFA or AS within the family, in the context of both attending a psycho-education group and in the wider context of families' life.

Aims of the study

1. In what ways, if any, will parents' narratives about their family and family relationships change?

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

2. What self-representations will parents' make in the narratives and in what ways, if any, will these portrayals change?
3. In what ways, if any, will elements of the psycho-education group feature in parents' stories?

Method

Choice of methodology

A central assumption of narrative research is that as individuals we give meaning to events in our lives by organising them as stories (Andrews, Squire & Tamboukou, 2008). As such, narrative methodologies focus on the way individuals talk about, and make sense of, life experiences (Dallos & Vetere, 2005; Riessman, 1993).

Repeated interview methodology enables the examination of narrative developments, and provides an opportunity for clarification of information. This allows for monitoring for consistency thus helping to establish internal validity (Elliott, 2005).

Participants

The current study formed part of a larger study, a pilot for a randomised controlled trial examining the efficacy of a post-diagnostic psycho-education group (PEGASUS) for children run with a parallel parent group (Appendix D). Families were recruited from a clinical population of children diagnosed at a Tier four ASD assessment centre within the previous three years. Due to the referral criteria of the centre children must have previously been seen by, and the under the care of, their local CAMHS or paediatrician.

Inclusion criteria were:

1. The child was aware of the ASD diagnosis.

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

2. The child was aged between 9 and 14 years and able to function in a group setting.
3. The family spoke sufficient English to participate in the group.

Exclusion criteria were:

1. The child's IQ was below 65.
2. Concurrent engagement in another psychosocial intervention.

Five families were recruited to the pilot study. All those who attended at least one group were interviewed and interviews were completed jointly where both parents attended.

Table 1 contains information about the characteristics of the participants and their children.

All children were aged between 11 and 14 years. Two had co-existing diagnoses of Attention Deficit Hyperactivity Disorder. All children were given the diagnosis following a multidisciplinary assessment using standardised assessments tools including the Developmental, Dimensional and Diagnostic Interview (Skuse, Warrington & Bishop, 2004) and the Autism Diagnostic Observation Schedule (Lord et al., 1989).

Table 1 - Participant characteristics

Family number	Respondent¹	Ethnicity of respondent	Diagnosis of child	Verbal IQ of child
1	Mother; Abigail	White Other	Atypical Autism	96
2	Mother; Beth	White Other	AS	106
3	Mother; Carrie	White British	AS	119
	Father; Craig	White British		
4	Mother; Dawn	Not Recorded	AS	98
5	Mother; Eve	White British	Autism	83
	Father; Evan	White British		

¹ Pseudonyms have been created to maintain confidentiality

Design

Participants were interviewed on two occasions, separated by approximately two months during which they participated in the parental psycho-education group. All interviews were digitally recorded and transcribed for analysis. A combination of structural (Labov & Waletzky, 1967) and thematic narrative analysis (Riessman, 2008) enabled the analysis of individual transcripts and examination of the contrasts and similarities of narrative themes within and between participants.

Materials

An interview protocol was created by following the five phases of narrative interview as proposed by Jovchelovitch and Bauer (2000):

1. Preparation: An interview frame (Appendix E) was developed in consultation with the autism centre. It was reviewed with a parent of child with ASD, independent to the study.
2. Initiation: The research interview opened with an overview of the central topic.
3. Main Narration: In the first interview, participants were invited to talk, without interruption, about their experience of parenting a child with ASD. This included their experience of diagnosis, the impact of having ASD in the family and their thoughts for the future. Parents were invited in the second interview to reflect on family life since their first interview.
4. Questioning Phase: The interviewer posed questions to elicit additional material around events mentioned by the participant. This space was also used to ask unanswered questions from the interview frame.

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

5. Concluding talk: Following the recorded interview, space was given for questions that added to the understanding of the context of the narrative. Responses were recorded by hand.

Procedure

A member of the research team gained parental written consent for participation. Parents were then contacted by the author to arrange a time to complete the interview. All interviews took place at their family home.

At the beginning of the interviews, the parents' understanding of the interview was clarified. Participants' right to withdraw from the interview and to abstain from answering any question was reiterated. Following the interviews, time was given for parents to ask questions.

Ethical Procedures

Ethical approval was obtained from an NHS research ethics committee (appendix B). R & D approval was also obtained from the local department (Appendix C). Participants gave verbal and written informed consent to participate (Appendix F, G).

Data Analysis

Following a detailed reading of the interview transcripts, the author analysed the data over four stages, combining elements of both structural and thematic narrative analysis. There is currently no broadly accepted singular approach to narrative analysis (Andrews et al., 2008). However, it is not unusual for these approaches to be combined within narrative research (e.g. Fleischmann, 2004; Hines, Balandin & Togher, 2011).

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

It is argued that analysis of narrative data should commence with examination of the structure of the narrative in order to move deeper than simply examining the content (Elliott, 2005). Labov and Waletzky (1967) proposed a framework for the structural analysis of oral accounts of personal experience. It is postulated that all narratives are constructed of an:

1. Abstract: an opening that explains the essence of the story.
2. Orientation: to time, location, and characters.
3. Complicating Action: the main event sequence that identifies the critical activity, often a crisis or turning point.
4. Evaluation: the meaning the teller assigns to the event.
5. Resolution: describes the outcome of the story.
6. Coda: ends the story and returns to the present.

A fully formed narrative contains these six elements, although not all narratives will contain all elements, nor must they occur in this sequential order (Riessman, 2008).

The aim of thematic narrative analysis is to identify common thematic elements arising from the narratives across research participants without dismantling the narrative (Riessman, 2008).

Stages of analysis

1. Individual narrative stage: Unique stories that formed the overall narrative were identified. The components of these stories were identified using structural narrative analysis.
2. Overall narrative stage: The unique stories were considered in the context of the whole narrative to construct a summary of the overall narrative.

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

3. Comparison of interviews by part: The themes of the summary narratives from interviews completed at the same point were compared and grand narratives of interviews one (time one) and interviews two (time 2) were created.
4. Compare and contrast: The two grand narratives were compared and contrasted in order to identify similarities and differences in parental narratives at the two time points.

Quality Assurance

A self-reflection interview was completed prior to completing the narrative interviews and a research diary was kept throughout (Appendix H). This allowed reflection on potential biases that may influence interpretation of the data. Independent audit was used to increase the validity of the findings. Here, a supervisor acts as independent auditor of the analysis trail (Dallos & Vetere, 2005). A conversation was held to discuss the coherence of the analysis and differences were resolved.

Results

This section begins with a summary of parents' unique stories which provides a context to the analysis that follows. The analysis of the grand narratives considers the themes that are consistent over time and those that develop. Finally, parents' attributions about these developments are explored.

An example of the process of analysis is contained in appendices I, J and K and diagrams of the grand narratives are contained within Appendix L.

Quotes used in this report will be identifiable by their family number. Quotes from the second interviews will be identifiable by the letter 'A' before the line number.

Overview of participants' stories across interviews

Abigail's narrative of determination

Abigail's narrative communicated her passionate determination as a mother, with stories full of the fights she encountered in her endeavour to ensure that her child reached her potential "*since this moment I knew the only thing that I've been thinking or doing is trying to work and do things to help her*" (lines 270-274). She explained the impact of the numerous hurdles she has encountered along the journey "*It is frustrating to trying to find the help for your child*" (line A235). Her narrative moved over time from this place of constant work to one where she felt that her child was beginning to manage more independently and enabled her to be more relaxed as a parent "*I can be more at home thinking okay she can do it, not suffering all the time thinking okay what is going to happen*" (lines A162-A164).

Beth's narrative of isolation to integration

A central theme to Beth's narrative was her experience of others' responses to her child's diagnosis. Her narrative told of the isolation from family and friends that she and her child experienced "*I don't know whether it was because I had told them...but [my son] didn't really see that boy as much as he used to*" (lines 113-115). She spoke of the stigma found in wider society "*if your son is acting up in public and people are like well, why is he acting up all weird*" (lines 121-122). Over time, she became able to tell others about the diagnosis and experienced some acceptance. However, she reflected on the lasting impact that her initial experiences had had on her ability to trust "*I think it's the real gradual process 'cos I think...it's hard to invite others to understand what you're going through*" (line A310-311).

Carrie and Craig's narrative of developing their own path

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

The narrative that Carrie and Craig told was one full of battles, being caught between services and not being understood “*when you’ve got professionals telling you no, it started to add doubts to, am I just being a paranoid mum...it does play with your mind which is, especially professionals, especially professionals*” (line 762-766). Their tumultuous journey of coping with these contradictions ultimately led them to trust in their own instincts as parents and develop their own path, “*sorted it out ourselves ‘cause come on like this was ridiculous*” (line 393). Their thoughts regarding diagnosis and the way they wished their family to exist had become more established by the second interview and there was a greater sense of confidence in their decisions, “*It works for us at the moment*” (lines A647-A648).

Dawn’s narrative of increasing understanding

Dawn’s narrative contained a story of growing understanding of ASD. It began at a point of her struggling to consider her child having a diagnosis and moved to her being able to think and learn about ASD. “*It does take a while for you to really sit down and think about and see how it affects, and that is the case and you need to deal with it*” (lines A248-A250). Within this narrative, she also communicated the need for knowledge in order to feel confident to battle with services, “*‘Cause I think the more knowledgeable you are the more you can do to help*” (lines A314-A315).

Eve and Evan’s narrative of broadening horizons

Eve and Evan’s narrative told how the event of their child being diagnosed, and their participation in the group enabled them to broaden their perspective on their child’s difficulties. Prior to the diagnosis, their stories had themes of uncertainty, fear, and stress as they interpreted events through the framework of their work experiences. The information

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

from the diagnosis enabled Eve and Evan to take a different perspective which resulted in them feeling that they had more understanding and hope for the future,

“I said, but she says things like I’m going to cut your arms off with a knife and [consultant] just looked at me and his facial expressions didn’t change and he just said ‘oh, I don’t suppose she means it’...And then you put it in perspective and he just says, I don’t suppose she means it, no she probably doesn’t actually and then all of a sudden it’s not quite so serious” (lines A676-A689).

Constancies in people’s stories over time

Analysis identified two central themes in participants’ narratives that remained consistent between the first and second interviews.

Struggles and Striving

Throughout all the interviews came themes of ‘battles’, ‘fights’ and a constant drive to do more for their child. For some, these battles were with themselves; Abigail and Evan told a story of their dilemma around whether obtaining a diagnosis was the right thing to do.

“I was probably reticent to have her labelled with something, whatever the diagnosis was. I just thought is that going to be of any benefit... In the end I sort of came round” (5, lines 531-542).

Dawn told a story of her husbands’ difficulties in living with undiagnosed ASD. Witnessing the very painful experiences he had encountered, such as bullying at work, resulting in her fear that her daughter may be equally as vulnerable,

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

“My husband never been diagnosed but I think he has Asperger’s and they are quite similar in certain ways and they get on very well...I saw that in there but I didn’t want it to be” (4, lines 74-83).

All parents spoke of the significant challenges they had faced in getting a diagnosis for their child. Beth, Carrie and Craig, and Dawn described difficulties in getting heard and understood by professionals, while others found themselves trapped between opposing views of services, as Eve and Evan described,

“we were getting that sort of the school was saying there was an issue and the medical profession...saying it it’s, there isn’t an issue” (5, lines 48-50).

All the parents spoke of a never-ending battle in trying to get support for their child following the diagnosis. It appeared that with every step forward there was another struggle needed to be resolved.

“you have to battle for every little thing that your child needs and I don’t think that has finished yet because I’m still battling with the school” (4, lines 238-240).

This lack of external support results in parents having to draw a huge amount from their own resources. Parents described it as *“frustrating too, trying to find the help for your child”* (1, line A235) and there was a feeling that *“you get kind of stuck”* (4, line 238). Some parents found that constant strain in being solely responsible for finding support left them feeling helpless. This also resulted in some feeling *“guilty ‘cos I feel like I could do more”* (2, lines A81-A82). However Evan held a more pragmatic view that the world will never be everything that you want, so you can only strive for being good-enough,

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

“it’s never gonna be the answer to everything just by saying that the child’s autistic...you’re never going to get ‘em every bit of support you’d like cos y’know I’m afraid the world’s just not like that” (5, lines A834-A837).

Society and culture

All families spoke of their experiences of the lack of others awareness about ASD.

They raised concerns that this creates a stigma associated with the diagnosis. Parents reflected that the isolation and exclusion from society that can occur as a result of the child not always conforming to societal norms,

“It is an isolated thing when it’s high functioning, because you have to bring them up in normal society. And if you’re in normal society you are very different. You are very different, your children are very different, very different” (5, lines A671-A674).

Beth also spoke of the difficulties that she experienced in getting others to understand her struggles due to her child presenting as very able. This contributed to her sense of feeling alone in the world,

“it’s really hard when people they go oh I’ve seen [child] and he seems fine to me, you know they don’t see him at those moments when it’s just really really bad” (2, lines 148-151).

Dawn reflected on her experience of being raised in a difference culture and expressed a sadness that her daughter is not accepted by society,

“I see it in a different way because my daughter is different and I feel that being different she’s more well accepted in my society than she is here” (4, lines 302-304).

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

Many of the parents gave examples of situations where they experienced negative responses from others, including family members. Eve described a particular occasion when a stranger decided to take matters into their own hands,

“I said ‘she’s on the autistic spectrum, she’s terrified of dogs’. You know and immediately I said that she said ‘I’m so sorry, I didn’t realise, I just thought she was badly behaved and the dog being there would teach her a lesson’” (5, lines 315-318).

Developments in people’s stories over time

Four themes of evolution and development were identified in the comparisons of the grand narratives.

Development of Self-belief

Abigail and Beth told stories that reflected their creation of meaning about why their child has ASD. Abigail told of it being God’s will as God knew that she would be a good parent to her child; Beth felt concerned that it was something that she had done wrong as a mother,

“I was like ‘oh my god it’s my fault, I feel so guilty’ she was like ‘its got nothing to do with you’ but I was like ‘did I not organise enough play-dates’ you know, I seriously just blamed myself” (2, lines 91-94).

Whilst this sense of responsibility was not as present in the second interviews, Eve and Evan reflected that understanding the diagnosis helped to begin to alleviate these fears,

“and then you understand...And you can not blame yourself so much and not feel that you’re responsible for it or y’know you must be doing something wrong” (5, lines A843-A845).

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

The initial interviews contained narratives of uncertainty around diagnosis, “*once you have the diagnosis what to do with it, how to do what you can do*” (2, lines 389-399). Over time, for many of the parents, the diagnosis had become a source of understanding,

“Definitely it must you know if you didn’t know what [child] had and you were forever guessing I guess you just wouldn’t know how to handle situations” (2, lines A237-A239).

Many of the parents spoke of their uncertainty about whether to adjust their natural hopes and dreams they hold for their children in light of the diagnosis,

“But you feel bad knowing that there is a diagnosis you feel a bit protective towards and thinking am I asking too much or am I not you know it’s quite tricky actually” (4, lines 103-105).

Dawn subsequently told a story, which was an example of her child’s achievements as compared to her peers. This narrative demonstrated her developed sense of confidence that she was making the right choices, and that it was right to hold onto hopes and expectations for her child.

“on her group of four classes she was the one that improve more in all subjects and they gave her award and little chocolates and all these nice things” (4, lines A124-A126).

Overall, the second interviews reflected the increased confidence of the parents. This appeared to result in altering the theme of the narrative stories from one of being constantly worried about not doing the right thing, “*I don’t know if I am doing well or not, I don’t know*”

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

(1, lines 425-426), to a more neutral position of recognising that mistakes happen and that you can only ever do your best,

“I did all the things that I could and people told me about. I don’t know was something much better because no body tell me, I didn’t find it on the internet or. It is difficult, but I think we did well” (1, lines A81-A84).

Humour had also begun to come into the narratives, being able to laugh about everyday events and enjoy the role of a parent appeared to have a positive impact on parents and move the story away from being problem saturated,

“I said to him could you help hanging the washing up and [son] went ‘I would mum but I’ve got that Asperger’s thing’...that was really funny, I thought give him points for trying you know” (3, lines A297-A301).

Development of understanding

Having ASD in the family initially seemed to be a very difficult experience, Eve and Evan described how stressful the unpredictability of behaviours was for the family,

“You know if she pulled one sock higher, I mean that was a monumental... you lived in sort of trying to anticipate what may go wrong or you know... And it it is a quite stressful you know” (5, lines 251-263).

In the second interviews, gaining a better understanding of the meaning of ASD led to it becoming a more an integrated part of daily life, as the individuality of the child had become an accepted part of the child’s identity.

“we’ve um, absorbed her, um diagnosis really into our day-to-day life. We’ve made allowances don’t we? We’ve changed things” (5, lines A260-A261).

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

Many of the parents spoke of a struggle in trying to understand ASD in the context of their own child. This uncertainty meant that they were occasionally unsure how to manage their child,

“we’re still kind of coming to terms with where he sits with him anyway what is it that is growing up, what is it that’s sibling rivalry, what is it that’s Asperger’s, what is it that he’s just a boy and boys and like boys” (3, lines 622-625).

There were many stories in the second interviews that demonstrated the different way they managed any difficult behaviour’s. Abigail spoke of taking time to understand why difficulties might be occurring,

“trying to think more if she’s doing the things with a reason, no, or not, this could be something more” (1, lines A27-A28).

Carrie and Craig, and Dawn spoke of gaining knowledge that enabled them to feel more confident in understanding ASD behaviour,

“This is a huge issue actually that if I don’t sort out the way I request him to do things or the way I tell him things then I’m going to always have problems with him” (3, lines A359-A392).

Beth very much experienced her child's difficulties as a loss of the parent-child relationship she had anticipated,

“I’ll always wish that he’d just come up to me and want to hold my hand and just give me a hug or give me a kiss and say ‘love you mum’” (2, lines 212-214).

Whilst this loss still appeared in the narrative of the second interview, Beth had developed a context of understanding to these behaviours which appeared to reduce the intensity of the pain of the loss,

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

“But its weird because I know he thinks it he must feel it its just he doesn’t show it um you know which is fine because you know some people are like that right they’re not as emotional right you know for whatever reason” (2, lines A122-A125).

Development of coping strategies

Parents often gave narrative stories that demonstrated the coping strategies that they used within their day-to-day lives. In the initial interviews, Abigail, Dawn and Eve and Evan spoke of a *“need to take one step at a time”* (4, line 175) where there was an emphasis on being *“happy for a little thing”* (1, lines 149),

“I’m a bit of a live for today anyway, not that we have no regard for the future, but you don’t know what is going to happen. You’ve got to make the most of what you’ve got at the moment” (5, lines 914-916).

There was also a sense that whilst things were difficult, things could be worse; Abigail and Beth compared their situation to other families that they knew,

“Of course I am worried with this thing with her with other people but I think it is something that much better to have this than other things no?” (1, lines 263-265).

In the second interviews, a new theme of active support was apparent. This new support was seen as a way of enabling the parents to cope with the everyday difficulties that parents without children with ASD would not understand. This theme occurred in two ways: One was in relation to support they had found in the group,

“good for me to meet the parents they were very nice and we can be in touch and if have a problem I can call one of them or I feel, I think this was good” (1, lines A115-A117).

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

The other manifestation was support that they had begun to find from family members. This development was particularly significant for Beth as she had a strong sense of feeling completely alone and isolated in the initial interview,

“the more I can try to make them understand the more they might be able to understand what I’m going through and what [child] going through. If you don’t share the information or you don’t try to share the stuff then how is anybody gonna help you” (2, lines A335-A338)

Carrie also highlighted that her son was becoming able to manage situations he found difficult. This was particularly important for them to witness as it gave a sense of the increased independence that their son was developing,

“he actually said to [relative] a few weeks ago, I’m sorry [relative], I’ve got Asperger’s and it means that I don’t always communicate properly and I can’t always understand when you communicate to me and I’m sorry about that...I thought wow what a wonderful thing” (3, lines A129-A134).

Development of Optimism

All the developments in the parents’ narratives appeared to influence parents’ perceptions of the future and created a sense of cautious optimism. Beth, placed this fear about the future in context,

“Actually one thing that I should add which is really really important is that it’s not curable, you see, that’s the thing, it’s not something you can like a sickness you can take medication or there’s a treatment for it. I mean there’s the various things you can do but there’s just no cure it’s a life long thing” (2, lines 293-298).

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

When considering the question of the future in the initial interviews, responses often demonstrated the fear the parents held.

“the future it’s a bit scary...its scary to think when she’s on her own and doing her own things, how is she going to deal with it” (4, lines 165-168).

When subsequently revisiting this question, there was a sense that the parents were more positive about the life that their child would have, that their child’s life would be in some way ‘normal’. For Dawn, this change in perception was a direct result of witnessing her being able to cope with the psycho-education group,

“I can see that she can do well so that can make me feel a little bit better about her future” (4, lines A131-A132).

For Abigail, there was initially a lot of concern from doctors around her child’s delayed development and there was much uncertainty about the prognosis for the future, *“And then he said, look she is very young we cannot be sure where she is”* (1, lines 22-23). The significant improvements in her daughter’s functioning led her to feel hopeful that the future may not be as difficult as predicted,

“she will always have something there that will be different. But if she knows and if she learns to live with it then I hope it won’t mean any problems for her you know” (1, lines 242-244).

There remained some apprehension about what the future may hold; Eve, Evan, and Beth were mindful of the difficulties their child may face in the future because of the ASD. When asked about what the challenges for the future might be, Beth spoke of concerns about difficulties in all areas of her child’s life,

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

“Probably just [child] becoming independent and just sort of taking care of himself and him being out, not living at home....and getting a job and making friends and having a partner” (2, lines 371-374)

However, there remained hope that their children would become increasingly independent,

“I mean, I can’t have him underneath my umbrella forever. And I don’t think he wants to be. Um, yeah. Cause it’s a tough world out there so we’ll see” (2, lines A411-A413).

Attribution of developments

Parents who had noticed changes and developments in their families told stories that indicated their beliefs about what had led to the development. Some parents attributed the developments to their participation in the psycho-education group whereas others felt that the developments were a result of changes within the family situation.

Group as normalising experience

All parents spoke of finding the group very helpful in normalising the experiences of parenting a child with ASD,

“so it was really handy listening to...hearing other people’s stories...really really handy cause you know you kind of think, well first of all, I’m not alone” (3, line A84-A89).

It was the first opportunity that they had had to be able to feel like a normal family, where they did not have to explain about the idiosyncrasies and challenges that come with having a child with ASD,

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

“I think it was nice that we were able to laugh about certain events that we would normally think, we’d pull our hair out at the time but hearing other similar stories and being able to sort of laugh about it in a way together was kind of a relief” (2, lines A43-A45).

For Dawn, the group provided an opportunity to have time and to be able to process the complex meaning of having a child with ASD,

“I did need that time to, to learn a bit more about it, and to think about it and accept it fully. And understand. Because sometimes you, I can read about it and er, I can receive the diagnosis, but it, not fully understand connecting the things all together” (4, lines A272-A275).

PEGASUS as a framework

Some of the parents’ spoke of being able to use the group as a framework of reference to support their child in understanding difficult situations,

“And I try to tell her about, OK [child] think about PEGASUS now, remember that in PEGASUS they told you that you have to to cope with the things sometimes that and she tries to, you know she tries to” (1, lines A32-A35).

Carrie and Craig spoke of how the group had provided a framework that enabled them to understand their child’s difficulties. Similar to Beth’s experience, it also helped to make talking about ASD more permissible within their family,

“it’s a lot better for us to be able to put it down, his behaviour or he said to me in the past, ‘why do I do that’ and you kind of don’t want to go [shrugs]...its been excellent

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

to kind of bring it, to kind of make it acceptable and accessible and OK to talk about”

(3, lines A323-A329).

Family situation improving over time

For other parents, other factors were felt to contribute to the developments in their narrative. These factors included time passing, witnessing improvements in their child and gaining increased support from family,

“I think some of it’s to do with, you’ve, just happened to be around, you know, here at this point... The timing more than anything else rather than there being any specific events” (5, lines A393-A399).

Four of the five families were undergoing significant changes in their lives at the point of the initial interview. Changes included substantial home improvement work and consideration of living in a different country. At the point of the second interview, decisions had been made and renovations completed which decreased the overall stress the families were experiencing,

“’cause was little bit of stress with all the all the building things and, but good. More or less the same things you know” (1, lines A9-A11).

Discussion

This study aimed to examine the process of parental narrative development in the context of attending a psycho-education group following their child being diagnosed with HFA or AS. The findings will be discussed in relation to the research questions and existing

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

literature. A consideration of the limitations of the study and the implications for future research and clinical practice will conclude the paper.

What ways, if any, did parents' narratives about their family and family relationships change over time?

Previous reviews highlight the significant impact that having a child with ASD has on the family (NICE, 2011a). Narratives of the parents clearly demonstrated the impact and disruptions that can occur in family life. This included the disruption to everyday routines, the stress of complex parenting and uncertainty caused by the unknown aetiology of behaviours.

In keeping with findings of previous research, themes of struggles and battles with services saturated many of the parent's narratives. Due to the service being a Tier 4 CAMHS, families were accepted only if assessment at a local service was inconclusive or if parents, services, or schools disputed the outcome. As such, the themes of struggles and battles may be unsurprising and it is possible that the strength of the theme is a reflection of the complexity of the presentation of the child or their family system. However, it does highlight the complex power dynamics that can occur between parent and services (Avdi et al., 2000). It appeared that all the families struggled with these dynamics at some point in their journey however, the narratives reflected the parents' increase in confidence and greater self-belief over time in their role as parent. This led to experiences they described as those of a 'normal family', where children were seen to be achieving in line with their peers, family relationships were growing stronger and families could laugh about everyday events.

The narratives also highlighted a strong theme of social isolation. Many parents told of difficult stories of experiences where they had felt misunderstood, excluded, and unfairly reprimanded for bad parenting. This finding highlights the 'hidden world' of HFA and AS (Chilvers, 2007); a world where families are left feeling unwelcome due to a lack of

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

understanding and awareness of the difficulties that individuals with HFA and AS experience (Farrugia, 2009).

Whilst these narratives of ‘struggles and striving’ and ‘society and culture’ remained consistent over time, the narrative of ‘understanding’ developed and evolved. The growing knowledge about ASD appeared to have a particular impact on behaviour management, which in turn appeared to positively affect family relationships. This finding is in keeping with research on parent-child relationships in the context of parent training programs. Parents receiving training report experiencing a greater parent-child attachment and increased involvement in their child’s life post-intervention (Wiggins, Sofronoff & Sanders, 2009).

What self-representations did parents’ make in the narratives and in what ways, if any, will these portrayals change?

Literature suggests that a diagnosis can change the social context of a family which can result in parents experiencing a loss of their personal identity, sense of self and role (Atwood & Gallo, 2010; Beresford, Rabiee & Sloper, 2007). When a child is diagnosed with ASD, parents’ roles adapt to include those of expert, manager and teacher (Mulligan, MacCulloch, Good & Nicholas, 2012). Stories within participants’ narratives highlighted the dilemma of needing to balance these multiple roles, which resulted in a concern about whether they were doing the ‘right’ thing. Over time, this uncertainty appeared to dissipate from the stories as the parents’ integrated the various roles into their personal narratives. Having a greater sense of cohesiveness appeared to enable parents to develop feelings of self-efficacy and confidence.

One’s narratives can only be understood in the context of personal beliefs that are held as an individual, family member and as part of wider society (Dallos & Draper, 2010). In this study, mothers in particular spoke about the impact of the diagnosis on their hopes and

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

dreams for their child and the guilt experienced from the fear that they had potentially done something to cause the difficulties. Whilst these narratives did not disappear over time, the context altered. The framework of the diagnosis and the understanding gained from it enabled the development of an alternative story away from one of loss and deficit to one where hopes and dreams felt achievable.

Increased self-efficacy has been demonstrated to have strong links with increased feelings of competency as well as some links to increased psychological functioning (Jones & Prinz, 2005). Whilst precise causes cannot be ascertained, narrative developments in both self-belief and optimism were identified in this study. In line with narrative theories (White & Epston, 1990), it could be hypothesised that holding a more cohesive personal narrative would be related to increased sense of well-being and hope for the future.

To what extent and in what ways did elements of the psycho-education group feature in parents' stories?

The psycho-education group appeared to become a framework for parents, as referring to 'PEGASUS' was considered an easier and more acceptable way of talking about ASD. Externalisation, where the 'problem' is separated from the identity of the individual, is one of the central aspects of narrative therapy (Morgan, 2000). For parents of children with HFA or AS the delay in understanding why their child experiences difficulties can lead to the parent believing that they are part of 'the problem' by being a 'bad parent', a message that is commonly reinforced by society (Huws et al., 2001). It appears that some parents used PEGASUS as an externalisation of the problems that can arise from having ASD, for example, referring to PEGASUS when trying to understand a difficult incident. Being able to separate both themselves and the identity of their child from ASD appeared to increase their sense of self-belief and confidence. Indeed, literature highlights that externalisation of a

SECTION B: THE DEVELOPMENT OF PARENTAL NARRATIVES

problem can often lead to the development of a sense of agency and control over the externalised difficulties (White & Epston, 1990). These alternative narratives are likely to be strengthened by the group experience, as narrative therapy highlights the significance of ‘outsider witnesses’ in thickening narratives through the creation of connections and the telling and retelling of the alternative narrative (Boston, 2009).

The psycho-education group also featured in all the parents’ narratives as a space that provided a sense of normality, and parents drew strength and support from that experience. There is much literature that indicates the isolation that parents can experience when they have a child with HFA or AS (e.g. Bromley et al., 2004). Participating in a parent group has been experienced as highly beneficial (Huws et al., 2001; Phelps et al., 2009). Indeed we are reminded of the therapeutic impact of the shared group experience in “ameliorating isolation” (Yalom, 2005).

Limitations

As with all narrative research, this study is limited by issues of validation and generalisation (Riessman, 1993). The small sample size means that findings cannot be generalised, but the concepts may be transferable to parents in similar circumstances. It is argued that narrative research does not strive to produce any conclusions of certainty, rather it aims for results to be grounded and supportable (Webster & Mertova, 2007). The author has made efforts to increase trustworthiness and coherence through the keeping of a reflective diary, the use of independent audit and examples of the process of analysis. Whilst the children of the parents involved in this study had a range of diagnoses under the ASD umbrella the rigorous clinical assessment, limited age range of the children, and their verbal IQ’s being in the average to high average range increases the trustworthiness of the findings (Volkmar & Klin, 2000).

Implications

These narratives demonstrate the clinical importance of recognising a parent's position in their personal process of adjustment, the coping strategies they are using, and the resources available to them, including knowledge and support networks. All the parents told narratives of a constant striving to cope and it will be important to understand how support services can best be tailored to parents' needs whilst recognising their strength and resilience. Opportunities for parents to gain a new framework of understanding will enable them to develop alternative, rich narratives. This should include the opportunity to meet other families in order for their experiences to be normalised and the alternative narratives witnessed. As parental and child adjustment may be closely linked (Boyer, Knolls, Kafkalas, Tollen & Swartz, 2000), it will be important to consider how to support both parents and children through the process of adjustment.

It will be important to continue to understand how parents' narratives develop in the context of psycho-educational groups, other group experiences and outside of groups in order to inform the development of support services. Clinical practice has highlighted the usefulness of a developmental-lifespan perspective in supporting families of children with ASD, particularly given that the family task of meeting milestones in a sequential, developmental trajectory is often disrupted in these families (Stoddart, 2005a). Adjustment and adaptation is likely to be part of a continuous life transition rather than one that is time limited (Power & Dell Orto, 2004). It would therefore be of value to explore these processes in a longitudinal context to understand how parents adjust and adapt to these family life-cycle transitions.

Conclusion

This study offers a first step in the construction of a theoretical knowledge of the developments of parental narratives following their child receiving a diagnosis of HFA or AS. Parental narratives of self-belief, understanding, and optimism developed and evolved over time. Parents' coping strategies evolved to include support from others. These developments appeared to stem from parents being able to use a different framework about ASD, which enabled them to develop alternative narratives about their families and themselves. Future research could continue to build upon these initial findings, which will contribute to the development of appropriate and relevant post-diagnostic support services for parents.

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SECTION C

Section C: Critical Appraisal

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SALOMONS
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Critical appraisal

What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

Undertaking this project has been an inspiring experience and I have felt very privileged to be a witness to the experiences of the parents I interviewed. However, it has also been a journey of significant learning and development. It has been an opportunity to consolidate skills gained from previous research experiences as well as a chance to learn many new skills, particularly in relation to narrative research.

This was my first experience of undergoing NHS ethics approval; it was one that I found to be, at times, confusing and time consuming. I was tremendously glad to be completing a project that was part of a wider study as I formed part of a wider team in completing this process. I was particularly grateful for this when attending the rather daunting ethics panel.

Whilst working as part of a wider study had its obvious benefits in relation to the ethics process and recruitment of participants, I also had to negotiate the complexities of working in partnership with many individuals whilst not working in the same location. This included devising new ways of using supervision when my external supervisor moved overseas to The Netherlands. However, this experience has given me confidence to be part of multisite, large research projects should the opportunity arise in the future.

The idea for this study was born out of my clinical experience of working in the autism assessment centre where this study was conducted. As such, this has been a valuable opportunity to develop the skills of integrating clinical practice and research. This is a task that is particularly important in the field of autism as clinical research has the smallest amount of funding of all Autism Spectrum Disorder (ASD) research (Singh, Illes, Lazzeroni

SECTION C: CRITICAL APPRAISAL

& Hallmayer, 2009) and it is acknowledged that there is a lack of dialogue between researchers, practitioners and families living with ASD (Charman & Clare, 2004).

One of the most significant skills I developed was that of completing narrative research. As there is no single agreed method to narrative analysis (Andrews et al., 2008), analysis risks being a 'piece-meal application' (Webster & Mertova, 2007). Whilst this study based the analysis on previous research, at times it felt a somewhat confusing and uncertain process. I feared losing key narratives from the participants and was concerned that I would not do their experiences justice. I was reminded that many of the narratives contained themes of uncertainty and anxiety and at times, it felt that the process of this study was reflecting some of their experiences. This experience taught me the importance of the research diary and regular supervision whilst conducting qualitative research. It will certainly be a lesson that I will take forward into any future research as I continue to develop the skills to manage this dilemma.

If you were able to do this project again, what would you do differently and why?

This study has been the first of its kind in the field of research in high-functioning autism (HFA) and Asperger's syndrome (AS). As such the choice of a narrative approach, which focuses on the participant's lived experience (Webster & Mertova, 2007), felt an appropriate methodology to begin to gain an understanding of this complex process. However, other methods of analysis were considered when designing this study.

Interpretive Phenomenological Analysis was considered as this also aims to explore how people make sense of significant life events (Smith & Flowers, 2009). However, this approach focuses on a specific event and therefore would potentially be more useful in understanding how parents made sense of the event of receiving the diagnosis for their child. Narrative analysis provided the opportunity to gain a broader perspective of the experience of

SECTION C: CRITICAL APPRAISAL

being a parent of a child with a diagnosis of HFA or AS and to explore the evolutions of narrative over time (Riessman, 1993).

As noted previously, there are many methods that have been proposed for the analysis of narrative data. As such, time was taken to consider the most appropriate form of analysis for this study. This enabled me to not only develop my theoretical knowledge of narrative research, but also gain skills in choosing the most appropriate methodology to answer the research questions. Following the re-reading of the transcripts, it was evident that there was not only a development in the narrative stories, but the stories themselves developed to include a greater number of 'Evaluation' and 'Resolution' stories. This indicates the presence of more 'fully formed' narratives (Riessman, 2008). Whilst this finding was gained from the researcher's experience of completing the structural narrative analysis, another branch of this project could examine this in greater detail through the application of both structural narrative analysis and content analysis. However, the combining of methodologies from different epistemological positions can be highly complex (Riessman, 1993).

Whilst narrative research should not be based on the same criteria of validity and reliability of quantitative methodologies, it remains important to be producing high quality research (Webster & Mertova, 2007). A number of steps were taken in this study to increase dependability of the data, meaningful analysis and stability and trustworthiness of the findings, all elements considered to be important in ensuring quality in narrative research (Elliott, 2005). As narrative research does not aim to identify a single 'truth', but recognises that there may be many 'truths' that are dependent on context and individual experience, triangulation is not considered to be a helpful form of increasing validity (Webster & Mertova, 2007) as it is in other qualitative research (Larkin & Thompson, 2012). However, the validity of the study may have been further increased through the use of member checks, where the interpretations and conclusions are taken back to participants for verification

SECTION C: CRITICAL APPRAISAL

(Riessman, 1993). It would be interesting to explore the use of this form of verification in future research, particularly as it has the potential of producing significant dilemmas if participants do not agree with the interpretations.

Clinically, as a consequence of doing this study, would you do anything differently and why?

Listening to the experiences of the parents highlighted to me the importance of providing time and space for parents both during and following the assessment of ASD. Whilst this is something that I always aim to achieve in my clinical work, clinicians are ever increasingly under pressure to deliver more in less time which has been demonstrated to have significant impact on the process of assessment for ASD (Karim, Cook & O'Reilly, 2012). This study has reminded me of the significant impact on the family where time to process the experience of, and information from, an assessment has not been provided. As such, if I were to work in any diagnostic service in the future, I would strive to ensure that there was space available in order to support the process of adjustment.

One of the most striking elements of the interviews for me was the depth of social isolation that the parents described as a result of having a child with ASD. I was not aware of how entrenched the societal discourse regarding parental responsibility for children's behaviour, currently is in society. I was genuinely shocked at some of the narratives parents gave about how they had been treated by not only strangers but also by their own family. Similarly, the extent of the parental guilt that was present in some of the interviews also took me by surprise. It will be important for me to keep hold of these experiences within my clinical work as a reminder that a child's diagnosis has implications at all levels of the system around that child. It therefore feels of even greater importance that in my clinical practice I

SECTION C: CRITICAL APPRAISAL

am able to provide a safe, non-blaming space for parents to be able to process their experiences.

Another powerful narrative from parents was that of the significance of seeing their child make achievements and the impact this had for parents' hope and optimism for the future. Studies have highlighted the importance that parents place on hope as the process of assessment is experienced as deficit-focused as it concentrates on the child's weaknesses (Mulligan et al., 2010). My experience of clinical practice in an ASD assessment team is also that, post-diagnosis, an immediate focus is placed on ensuring that the child is in receipt of appropriate support. This again focuses more on what the child is unable to do, rather than the child's strengths. I therefore would wish to ensure that in my clinical work I balance the need to address the child's weaknesses but not lose sight of the child's and the family's strengths and abilities.

If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

The current study provides a first look at the process of narrative development in parents of children with HFA or AS. As such, further research will be required to continue to develop the theoretical evidence-base in this area. Completing qualitative research examining narrative development in parents not receiving formal group interventions will be an important step in understanding the role that psycho-education groups might play in the development of alternative narratives. Given parents' reporting that the psycho-education group provided a normalising experience for them, and it was this that some parents attributed to supporting changes in their narratives, it would be of interest to examine narrative development in the context of a parental group that was not psycho-education based.

SECTION C: CRITICAL APPRAISAL

Another area of interest would be to explore parental narratives longitudinally. Narratives are understood not only to act as a framework through which to understand significant events and experiences, but also as flexible entities that adapt to incorporate new experiences (McAdams & Cox, 2010). It would therefore be of interest to understand how parents adjust and adapt to significant events such as secondary school transition and the child's transition into adulthood which are known to be extremely difficult times for children with ASD (Howlin, 2004; Jindal-Snape, Douglas, Topping, Kerr & Smith, 2006).

This study was completed in the context of a pilot for a large randomised controlled trial (RCT) of a post-diagnostic psycho-education group for children and parents. As such, results from this study have been fed back to the research team to inform the development of the groups for the RCT. During a research meeting, the team reflected that the parents were able to very quickly engage in telling their own story in the group setting and clinicians wondered what role, if any, the narrative interview they completed prior to the first session had on engagement. Indeed, during the interviews some parents told me that it was the first time they had discussed some of the areas of conversation as a couple. A possible area of further research might therefore be to explore the role, if any, of a narrative interview on parents' participation in a psycho-education group. Indeed, given the evidence for the effectiveness of single-session narrative therapy (e.g. Stalker, Horton & Cait, 2012), it would also be interesting to explore whether the act of completing a narrative interview impacted upon narrative development.

Whilst there is still a phenomenal amount to be learnt about the parental experience, there is also a small, but growing literature base on the adaptation of siblings of children with ASD (Macks & Reeve, 2007). In order to develop services that support the child's whole system, it would be beneficial to develop our understanding of the process of adjustment in the context of the whole family, including any siblings without ASD.

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SECTION D

Section D: Appendix of supporting material

SEPTEMBER 2012

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix A: Literature review search strategy

Literature for review was identified using computer based searches of the following journal databases:

SAGE Journals
Web of Knowledge
ScienceDirect
PsychINFO

Additional papers were identified through internet searches using Google Scholar and NHS Evidence and manual reviews of references and citations.

All searches were completed using the following search terms:

Experience*
Diagnosis
Parent*

Aspergers Syndrome OR Asperger* OR Autism OR Autism Spectrum Disorder OR Autism Spectrum Condition OR ASD OR ASC OR 'Autism Spectrum Disorders' OR 'Autism Spectrum Conditions' OR 'High Functioning Autism' OR HFA

In order to identify literature relevant to psycho-educational interventions, the literature search for this section of the review included the terms:

Psychoeducation OR psycho-education OR 'psycho education'

For the purposes of this review, psycho-education was defined as an educational post-diagnostic educational intervention for parents of children with ASD without comorbid learning disability. These interventions had to be facilitated by clinical professionals rather than peers and outcome data, either quantitative or qualitative must have been gathered and analysed.

The electronic search was completed without date limitations. The final electronic search was run in September 2011.

Criteria for inclusion

Papers were included in the review if they fulfilled the following criteria:

Reference to child with ASD
Parents
Related to the experience of diagnosis or living with ASC
Psycho-education for parents
Outcome data for parents

Papers were excluded from the review if they only contained reference to young people with autism and a learning disability. This is due to the many additional difficulties that children with autism and a learning disability usually experience and the possible differences in aetiology such as chromosomal abnormalities such as Turners Syndrome. Due to the prevalence of co-morbid mental health difficulties, papers were not excluded if children had co-morbid mental health or neurodevelopmental diagnoses.

SECTION D: APPENDIX

Outcome data was defined as either qualitative or quantitative data collected and analysed by the authors.

Results

The total number of papers identified in the initial search was 103. These were grouped according to the theme of the paper.

Following application of the inclusion and exclusion criteria the following numbers of paper were retained for review:

Receiving a diagnosis: 16 papers

Living with ASD: 17 papers

Psycho-education interventions for parents: 6

Appendix B: NHS Ethics approval letter

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SECTION D: APPENDIX

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SECTION D: APPENDIX

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Appendix C: Research and Development approval letter

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Appendix D: PEGASUS Protocol

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SECTION D: APPENDIX

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Appendix E: Interview Frame

Interview 1

Today is a chance to think about your experiences as parents in this journey of assessment and diagnosis and how you feel this has, or has not, impacted on life as a parent and in the context of the family. I wonder if there is a natural starting point of your story?

1. Thinking about the first time that the parent went to seek help for their son/daughter?
 - What prompted this?
 - What was this experience like?
 - How did they feel about seeking help?
 - What did they feel, as parents, was happening at this time for their son/daughter?
 - What did they take these events to mean about their son/daughter?
 - What did they take these events to mean about themselves as parents?
 - What did they take these events to mean about the family as a whole?
2. What was family life was like at this time?
 - What did this mean for them?
 - What was this like for their son/daughter?
 - What was happening within the family during this time?
3. What were the thoughts and beliefs held prior to their son/daughter receiving the diagnosis?
 - About themselves as parents?
 - About the child?
 - About the family as a unit?
4. What was the experience of receiving a diagnosis for their son/daughter like?
 - Was this the same for all members of the family?
 - What has this meant for them as parents?
 - What do they feel it has meant for their son/daughter?
5. Does having a child with an ASC within the family have an impact on parent's thoughts and beliefs about the family?
 - On their beliefs about parenthood?
 - On their beliefs about families?
 - On their hopes or expectations for themselves and the family?
6. How do they see the family's journey that is ahead?
 - What is their role, as parents, in this?
 - What do they feel to be the challenges/difficult times?
 - What do they see to be the exciting times?

Interview 2

Today is an opportunity to think about what life has been like for you and for your family since we last met as well as to reflect on the conversation we had previously. I wonder if there is a natural start to your thoughts on this?

1. What has family life been like since the last meeting?
 - What has been happening within the family?
 - What has this meant for them as parents?
 - What has this meant for the family?
2. What has been significant for the parent's during this time?
 - Are there any particular days that stand out since the last meeting?
 - Have they been able to integrate this significant experience into their daily lives?
 - Do they feel that this has had any impact on themselves or the family?
3. Do their thoughts and beliefs about the family in relation to having a child with a diagnosis of an ASC remain the same today as previously?
 - On their beliefs about parenthood?
 - On their beliefs about families?
 - On their hopes or expectations for themselves and the family?
4. Looking back on family life prior to their son/daughter receiving their diagnosis, what are their thoughts on the experiences the family had?
 - What meaning do they give to these experiences?
 - How does this meaning reflect on the roles individuals hold within the family?
 - Do all members of the family share these interpretations?
5. Do their feelings about the future remain the same as previously?
 - What is their role, as parents, in this?
 - What do they feel to be the challenges/difficult times?
 - What do they see to be the exciting times?
6. What role, if any, have the groups provided?
 - What has been the experience of coming to the groups?
 - Has the experience of being part of the group led to any changes in the way they view themselves, the child or the family?

Appendix F: Parental Information Sheet

Information Sheet for Parents and Guardians

Evaluating a group intervention for children with an autism spectrum disorder

We would like to invite you and your child to take part in our research project. Before you decide, we need to tell you why the research is being done, and what would be involved in taking part. One of our team will go through the information sheet with you and your child and answer any questions that you have - this should take about 20 minutes. Part I of this information sheet explains why we are doing the study and what would be involved in taking part. Part II gives some more detailed information about the study.

Part I

What is the purpose of the study?

When a child receives an ASD diagnosis this should be beneficial to them and their family. It should help them better understand their difficulties and support needs. However we know that for some young people and their families, an ASD diagnosis can be confusing and upsetting.

As a result we have developed a programme aimed at maximising the positive effects of an ASD diagnosis. It is called PEGASUS. This is a way of working with young people and their parents to help them better understand ASD. We hope that this will help young people feel more confident about themselves. However we do not yet know if PEGASUS really helps. This study is aimed at finding out whether it is a useful programme. We do this using a randomised trial.

What is a randomised trial?

Sometimes we do not know whether a particular treatment actually works. To find out we need to put people into groups, and give one group the treatment and the other group no treatment. Then we can compare the groups to see if the group that received the treatment is better off. In order to make sure that the groups were the same to start with, each family is put into a group by chance (by randomisation).

In our randomised trial there will be two groups - one will receive PEGASUS and the other will not receive any extra support. This means that any family who joins the study has a 50% (one in two) chance of being selected to receive PEGASUS.

Why have I been invited?

We have invited you to take part in our study because we know that your child has been diagnosed with an ASD. In total we aim to involve 40 families who have a child with ASD.

Do I have to take part?

No - it is up to you and your child to decide whether or not to join the study. If you do decide to take part we will ask you and your child with ASD to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What is PEGASUS?

PEGASUS is a programme designed to help young people who have an ASD learn more about the condition and how it is relevant to themselves. PEGASUS believes that parents have a crucial role to play in this process, and aims to offer them support and information too. The programme

SECTION D: APPENDIX

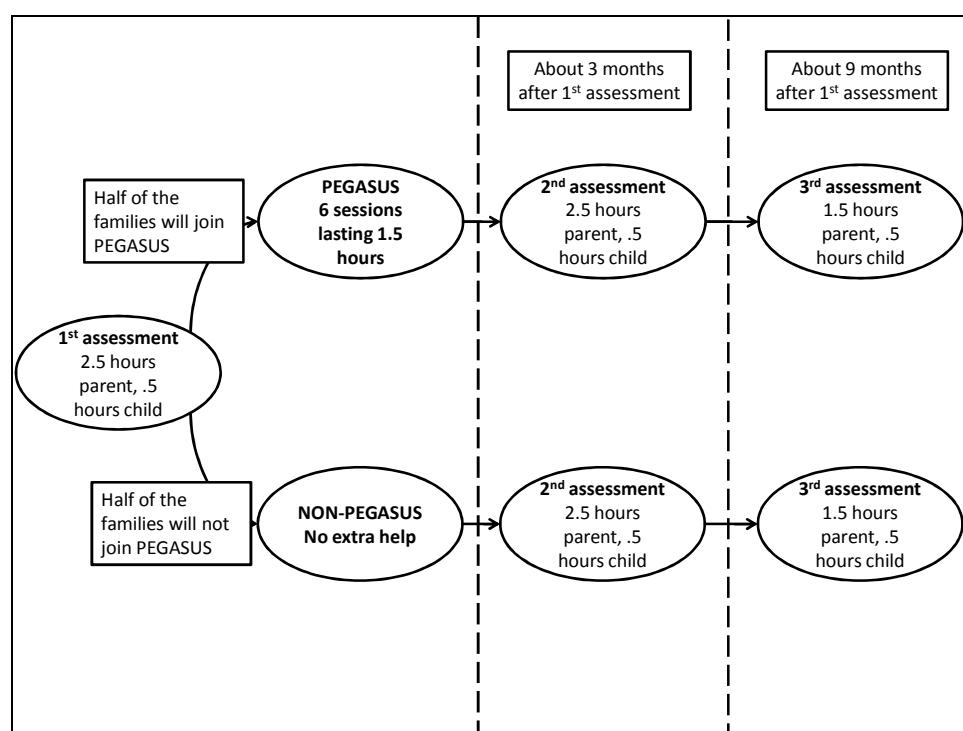
involves six weekly sessions each lasting one and a half hours. There are parallel sessions for children and parents. PEGASUS is a group-based programme, with a maximum of 6 children per group.

In the young persons' group there is a mixture of teaching and playful activities. Sessions have a particular theme (e.g. 'getting along with people', 'feeling good about myself'). In each session there will be some teaching from the group facilitators to give information. There will be activities designed to help young people learn in an engaging, child-friendly way (e.g. 'working in pairs to come up with a picture of the good things about ASD'). In the parents' group there will be a mixture of teaching and discussion, linked to the theme of the young persons' group.

All groups will be facilitated by a clinical psychologist, experienced with working with children with ASDs. There will be support from at least one additional psychologist in each group.

What will happen if we do decide to take part?

The picture below shows what will happen if you and your child decide to take part in the study.



- ❖ First assessment - You will be asked to spend about an hour completing some questionnaires about the strengths and difficulties your child has. It is possible you will also be asked to do a 30-minute interview with one of the team about your child's ASD. Also we will ask your child to fill in some questionnaires, which will take around 30 minutes. This assessment will take place at
- ❖ Group allocation - After the first assessment you will be told whether or not you and your child will receive the PEGASUS programme.
- ❖ PEGASUS - for those families randomly selected to receive PEGASUS there will be a significant time commitment. The programme involves six weekly sessions, which each last 90 minutes. During these sessions there will be a child group and a parent group which run alongside each other. All sessions will be held at . We would also like to complete two interviews with parents, at the beginning and end of the

SECTION D: APPENDIX

programme. These will last approximately 1 hour each and take place either at
or at the family home.

- ❖ Non-PEGASUS - the families not chosen for PEGASUS will not receive any additional support or intervention from the study. Of course, if they are receiving help outside of the study, this will carry on as usual.
- ❖ Second assessment - this happens after PEGASUS has been completed, about 8 weeks after the first assessment. Both people who received PEGASUS and those who did not will be asked to complete the second assessment. The second assessment involves parents and children filling in the same questionnaires as in the first assessment.
- ❖ Third assessment - This happens six months after the second assessment, and includes the same questionnaires for parent and child as were used at the first and second assessments.

Will we receive expenses?

Yes - we will cover any travel expenses from taking part, such as coming to the first assessment and attending the PEGASUS sessions.

What are the possible disadvantages and risks of taking part?

The PEGASUS programme involves discussing the advantages and disadvantages associated with having an ASD. Whilst this will be done in as constructive a manner as possible, facilitated by clinical psychologists, it is possible that some children could find this distressing. Similarly parents may find it distressing when considering the negative aspects of ASD. The group nature of the PEGASUS programme will mean that sensitive information could sometimes be shared between children and between parents. As a result we will ensure there are clear group rules about respecting the confidentiality of others.

Those families selected for PEGASUS will have to make a considerable time commitment to attend all six sessions.

What are the possible benefits of taking part?

We do not yet know if PEGASUS will benefit children with ASD and their parents - that is why we are doing this study. However, we have designed it to be as child-friendly as possible and we hope that many young people will enjoy attending. We also hope that parents will find it helpful meeting others facing similar challenges to themselves.

Whilst those not selected for PEGASUS will not receive any additional support as a result of joining our research, the information we get from this study may help improve the future treatment of people with ASD.

What if there is a problem?

Any concerns or complaints about how you and your child have been dealt with during the study or about any possible harm you may have experienced will be addressed. Detailed information on this is given in Part II.

Will my confidentiality be respected?

Yes - we will follow ethical and legal practice and information about you will be handled in confidence. Please see Part II for more detailed information.

Part II

What will happen if my child or I do not want to carry on with the study?

SECTION D: APPENDIX

You are free to withdraw from the study at any time, and you do not have to give any reason for doing this. If you did withdraw we would ask you if we could keep information we had already collected about you and your child.

What if there is a problem?

If you have a concern about any part of the study you should ask to speak to the researchers who will do their best to answer your questions (). If you remain unhappy and wish to complain formally, you can do this by contacting the Patient advice and liaison service (PALS) at

In the unlikely event that you or your child is harmed during the research and this results from negligence then you may have grounds for a legal action against , but you may have to pay your legal costs. The normal NHS complaints mechanisms will be available to you.

Will my confidentiality be respected?

We will respect your confidentiality and that of your child, and will not pass information outside of the team. People taking part will be given a code so that your name will not be linked to any of the information you give us. Only members of the research team will have access to your anonymised data.

Interviews with parents will be audiotaped and transcribed to allow for analysis of the conversation. All recordings will be destroyed once they have been transcribed. Quotes from the interviews may be used in the final report, however all identifying factors will be changed.

If you decide to join the study and are selected for PEGASUS, we will ask your permission to tell your GP that you are receiving this input.

What will happen to the results of the trial?

In order to maximise the benefits from our research we will seek to publish the study's results in a scientific journal, and to present our findings at professional conferences. We will ensure that no individual participant is identifiable in the reports we produce.

Who has reviewed this study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Research Ethics Committee.

Please address any questions, comments and concerns to

Appendix G: Parental Consent Form

CONSENT FORM FOR PARENT OR GUARDIAN

Participant Identification Number:

Evaluating PEGASUS - a group intervention for young people with an
spectrum disorder

autism

1. I confirm that I have read and discussed the information sheet dated
for the above study and have had the opportunity
to ask questions

2. I understand that my child's and my participation is entirely voluntary and
that we are free to withdraw at any time, without giving any reason,
without my medical care or legal rights being affected.

3. I understand that relevant aspects of my personal data (e.g. name,
address, telephone number), relevant parts of my child's medical records
and data collected during the study may be looked at by responsible
individuals from

where it is relevant to us taking part in
this research. I give my permission for these individuals to have access to
my records.

4. I give consent for my child to take part in the above study.

5. I agree to take part in the above study.

Name of Parent/Guardian

Date

Signature

Name of person taking consent
(If different from researcher)

Date

Signature

If you have any questions at all, now or later, please ask the person who gave you this sheet.
Alternatively you can contact

1 copy for participants – 1 for researcher

Appendix H: Research Diary

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SECTION D: APPENDIX

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Appendix I: Interview Transcript, Interview 2

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Appendix J: Overall Narrative Analysis, Interview 2

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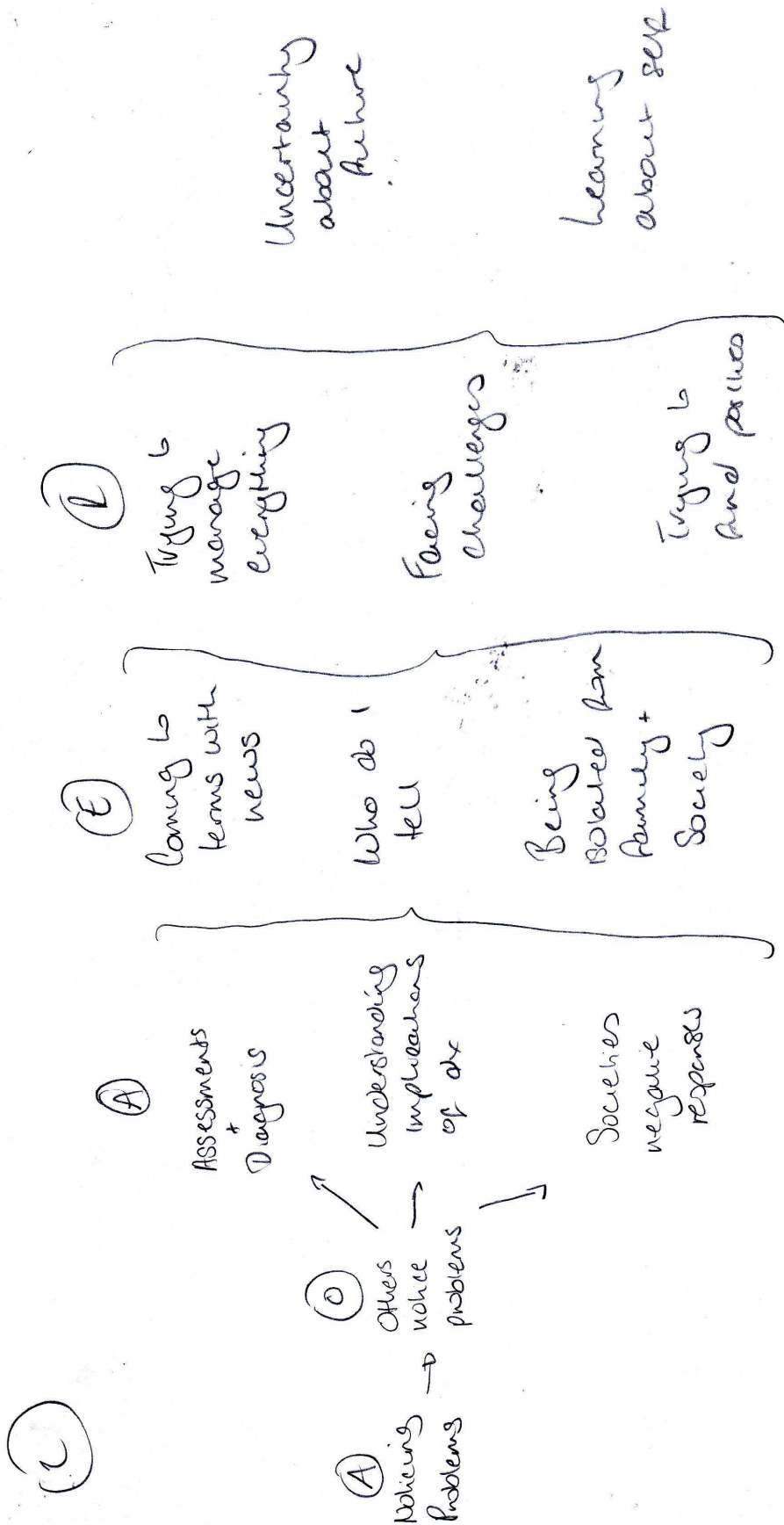
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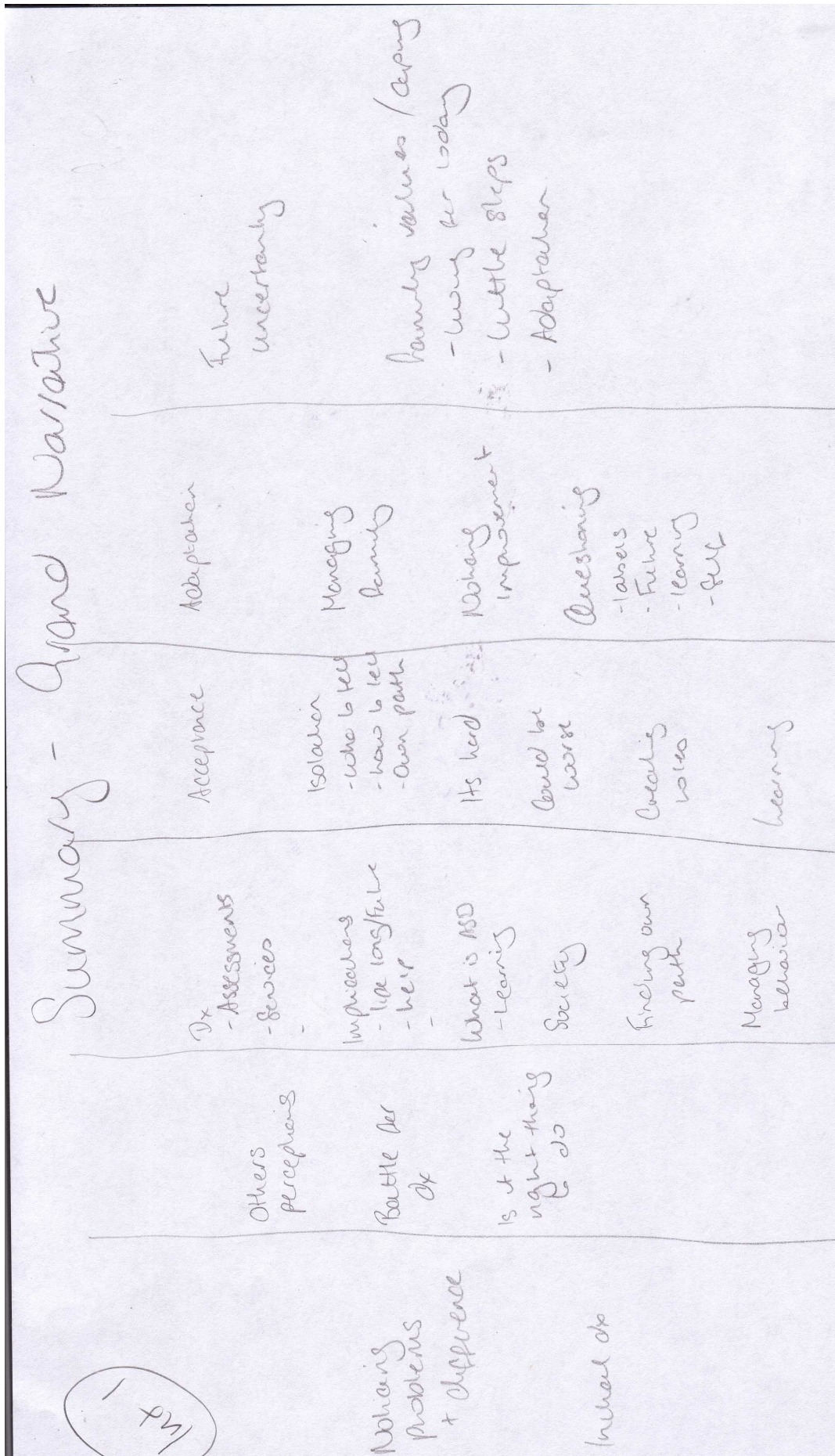
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Appendix K: Summary Narrative, Interview 2



Appendix L: Grand Narratives

Time 1



Time 2

Int. 2.

Summary - Grand Narrative

Adjusting to ASD	Identifying with others	Negotiating independence	Adjustment	Support network	Always showing
Individual vs ASD	Feeling alone in Family	Understanding & Managing ASD	Learning	She is OK	Need for ongoing support - shared knowledge learning process
Normalising experience	Lack of awareness	Understanding oneself	Acceptance	Positive changes	Developing our identity
Sharing the dx		Battles to get help	Society + Stigma	Understanding ASD	Optimism for independent future
		Changing relationships	Creating a lifestyle	Hopes for future	
		Sharing the dx	Doing best	Less concern	
		Wanting to do more	Needing support	Creating our norm	

Appendix M: End of Study Letter and Report

July 2012

Dear ,

RE: Can psycho-education improve the well being and functioning of young people with an autism spectrum condition? A randomised controlled trial.

REC reference number:

As principle investigator for the above study, I am writing to share the research findings of the qualitative study that formed part of the pilot for the randomised controlled trial.

Please find attached a report summarising the findings of the study examining narrative developments in parent of children with high-functioning autism and Asperger's syndrome.

Thank you for your support in enabling this project to take place. I believe that is arranging a meeting for me to be able to meet with the PEGASUS research team in the near future to discuss these findings further.

I look forward to seeing you then,
Best wishes,

Trainee Clinical Psychologist

The development of parental narratives following diagnosis of a child with an autism spectrum disorder.

Summary of Findings

Introduction

Parents experience a vast range of emotions following their child being diagnosed with an Autism Spectrum Disorder (ASD) (Mansell & Morris, 2004; Nissenbaum et al., 2002). There is currently little understanding of the process of parent's narrative development following diagnosis being given and parents describe a significant lack of adequate post-diagnostic support.

Parents' search for meaning about their child's behaviours is observed in the efforts they undertake to get a diagnosis for their child, their responses to it, and their striving to understand behaviours in the new context. Without a frame that provides context to our experiences, they cannot be made meaningful (White, 1995). A lack of meaningful framework often results in individuals feeling helpless, less optimistic and having less problem solving abilities (White & Epston, 1990). By increasing knowledge and understanding through exploration and reflection, alternative narratives can be created, which provides a new framework through which to interpret events and attribute meaning (Morgan, 2000).

There is currently little post-diagnostic support for parents of children with High Functioning Autism (HFA) or Asperger's Syndrome (AS) (NAS, 2010), which often leaves parents struggling to negotiate the process of adjustment by themselves (Huws et al., 2001). Psycho-education is seen as the primary intervention in supporting adjustment following the diagnosis of illness or disability in a child (Spinks, 2009). However, there is currently a lack of empirical studies examining the efficacy of psycho-education interventions for parents of children with HFA and AS (Pillay et al., 2011). Uncontrolled evaluation studies have demonstrated that parents report increased confidence (Pillay et al., 2011), self-efficacy (Sloman & Leef, 2005; Sofronoff & Farbotko, 2002) and psychological well-being (Roberts & Pickering, 2010).

Aims

The study sought to examine the narratives of parents of children with HFA and AS within the context of their participation in a psycho-education group. It was hoped that the present study would add to current knowledge by illuminating the process of parental meaning-making of a diagnosis of HFA or AS within the family.

Method

The current study formed part of a larger study, a pilot for a randomised controlled trial examining the efficacy of a post-diagnostic psycho-education group (PEGASUS).

All seven parents who participated in the psycho-education group were interviewed, using a narrative interview frame, on two occasions, separated by approximately two months during which they participated in the parental psycho-education group.

Following a detailed reading of the interview transcripts, the author analysed the data over four stages, combining elements of both structural (Labov & Waletzky, 1967) and thematic (Riessman, 2008) narrative analysis. This enabled the analysis of individual transcripts and examination of the contrasts and similarities of narrative themes within and between participants.

Results

Analysis identified two themes that remained constant across the time period; 'struggles and striving' and 'society and culture'. The narratives of the parents clearly demonstrated the impact and disruption that can occur in family life. In keeping with the findings of previous research, themes of struggles and battles with services saturated many of the parent's narratives. All families spoke of their experiences of the lack of others awareness about ASD. Parent's narratives demonstrated the isolation and exclusion from society they had experienced, often occurring as a result of the child not conforming to societal norms.

Four themes developed over time; 'self-belief', 'understanding', 'coping strategies', and 'optimism'. Over time the narratives appeared to show the parents having increased confidence and greater self-belief in their role as parent. This led to experiences they described as those of a 'normal family'. Stories within participant's narratives highlighted the dilemma of needing to balance the multiple roles of parent, carer, expert, manager and teacher. This resulted in parent's feeling concerned about whether they were doing the 'right' thing. Over time, this uncertainty appeared to dissipate from the stories as the parents' integrated the various roles into their personal narratives. Having a greater sense of cohesiveness appeared to enable parents to develop feelings of self-efficacy and confidence.

Participant's narratives also highlighted the increased understanding parent's held about ASD. Narratives from the second interviews highlighted the greater confidence parents had in managing difficult situations through being able to consider the difference between their child as an individual and difficulties arising as a result of the ASD. Mothers particularly spoke about the impact of the diagnosis on their hopes and dreams for their child. Whilst these narratives did not disappear over time, the framework of the diagnosis and the understanding gained from this enabled the development of an alternative story away from one of loss and deficit to one where hopes and dreams felt achievable.

The psycho-education group appeared to help some parents to develop a framework for a more positive narrative. It appeared that to refer to 'PEGASUS' was an easier and more acceptable way of talking about ASD and the child's strengths and weaknesses. The psycho-education group also featured in all the parent's narratives as a space that provided a sense of normality and parents drew strength and support from that experience.

Conclusions

This study offers a first step in the construction of a theoretical knowledge of the developments of parental narratives following their child receiving a diagnosis of HFA or AS. Parental narratives of self-belief, understanding and optimism developed and evolved over time. Parents' coping strategies evolved to include support from others. These developments appeared to stem from parents being able to use a different framework about ASD which enabled them to develop alternative narratives about their families and themselves. Future research could continue to build upon these initial findings which will contribute to the development of appropriate and relevant post-diagnostic support services for parents.

Dissemination

This study was completed as part of the requirements for the researchers' Doctorate in Clinical Psychology (DClinpsy). It is planned to submit these findings for publication in a peer-reviewed journal. The study was also completed as part of an RCT examining the efficacy of a psycho-education group for young people and their parents. This larger study remains ongoing and it is planned to incorporate, where appropriate, the findings of this study into the development of the psycho-education program.

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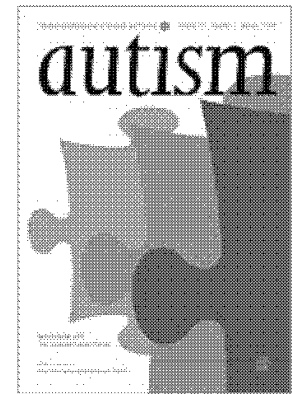
Appendix N: Submission Guidelines for Journal



Manuscript Submission Guidelines

Autism: The International Journal of Research and Practice

1. [Peer review policy](#)
2. [Article types](#)
3. [How to submit your manuscript](#)
4. [Journal contributor's publishing agreement](#)
 - 4.1 [SAGE Choice](#)
5. [Declaration of conflicting interests policy](#)
6. [Other conventions](#)
7. [Acknowledgments](#)
 - 7.1 [Funding acknowledgement](#)
8. [Permissions](#)
9. [Manuscript style](#)
 - 9.1 [File types](#)
 - 9.2 [Journal style](#)
 - 9.3 [Reference style](#)
 - 9.4 [Manuscript preparation](#)
 - 9.4.1 [Keywords and abstracts: Helping readers find your article online](#)
 - 9.4.2 [Corresponding author contact details](#)
 - 9.4.3 [Guidelines for submitting artwork, figures and other graphics](#)
 - 9.4.4 [Guidelines for submitting supplemental files](#)
 - 9.4.5 [English language editing services](#)
10. [After acceptance](#)
 - 10.1 [Lay Abstracts](#)
 - 10.2 [Proofs](#)
 - 10.3 [E-Prints and complimentary copies](#)
 - 10.4 [SAGE production](#)
 - 10.5 [OnlineFirst publication](#)
11. [Further information](#)



Autism provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

1. Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

[Back to top](#)

2. Article types

The Journal considers the following kinds of article for publication:

1. Research Reports, describing new experimental findings;
 - (a) *Full papers*
 - (b) *Short reports requiring rapid dissemination* (2,000 words maximum, no more than 2 tables and 15 short references)
2. Review Articles. The Editors wish to encourage the following types of review, but request that authors contact them in advance:
 - (a) *general reviews that provide a synthesis of an area of autism research;*
 - (b) *critiques - focused and provocative reviews that are followed by a number of invited commentaries, with*

SECTION D: APPENDIX

a concluding reply from the main author;

3. Letters to the Editors. Readers' letters should address issues raised by published articles or should report significant new findings that merit rapid dissemination. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

Full papers are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, references, tables, biographical statement, etc.). We are reluctant to burden our referees with very long manuscripts. Editors may ask authors to make certain cuts before sending the article out for review.

[Back to top](#)

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Autism is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/autism> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit [ScholarOne Online Help](#).

All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

[Back to top](#)

4. Journal contributor's publishing agreement

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4.1 SAGE Choice

If you wish your article to be freely available online immediately upon publication (as some funding bodies now require), you can opt for it to be included in SAGE Choice subject to payment of a publication fee. The manuscript submission and peer reviewing procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE Choice. For further information, please visit [SAGE Choice](#).

[Back to top](#)

5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. *Autism* does not require a declaration of conflicting interests but recommends you review the good practice guidelines on the [SAGE Journal Author Gateway](#).

[Back to top](#)

6. Other conventions

We would prefer to use the term 'people with autism' or 'people with autism spectrum disorders or conditions'. We would also prefer the term 'typically developing' rather than 'normal'.

[Back to top](#)

7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

SECTION D: APPENDIX

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the [Research Information Network \(RIN\)](#), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with "and" before the final funder. Thus:

This work was supported by the Wellcome Trust [grant numbers xxxx, yyyy]; the Natural Environment Research Council [grant number zzzz]; and the Economic and Social Research Council [grant number aaaa].

In some cases, research is not funded by a specific project grant, but rather from the block grant and other resources available to a university, college or other research institution. Where no specific funding has been provided for the research we ask that corresponding authors use the following sentence:

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity dependent on the peer review policy of this journal outlined above, you can withhold this information until final accepted manuscript.

For more information on the guidance for Research Funders, Authors and Publishers, please visit: <http://www.rin.ac.uk/funders-acknowledgement>

[Back to top](#)

8. Permissions

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[Back to top](#)

9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

9.2 Journal Style

Autism conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

9.3 Reference Style

Autism operates a Sage Harvard reference style. [Click here](#) to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

SECTION D: APPENDIX

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

Artwork, figures and other graphics such as tables should be uploaded through SAGE's Online Submission System alongside the main body of the text, as a separate file to ensure best quality in production. For further guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

9.4.4 Guidelines for submitting supplemental files

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

9.4.5 English Language Editing

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

[Back to top](#)

10. After acceptance

10.1 Lay Abstracts

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane (l.crane@gold.ac.uk). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families).

These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

10.2 Proofs

We will email a PDF of the proofs to the corresponding author.

10.3 E-Prints and Complimentary Copies

SAGE provides authors with access to a PDF of their final article. For further information please visit [Offprints and Reprints](#). We additionally provide the corresponding author with a complimentary copy of the print issue in which the article appears up to a maximum of 5 copies for onward supply by the corresponding author to co-authors.

10.4 SAGE Production

At SAGE we place an extremely strong emphasis on the highest production standards possible. We attach high importance to our quality service levels in copy-editing, typesetting, printing, and online publication (<http://online.sagepub.com/>). We also seek to uphold excellent author relations throughout the publication process.

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10.5 OnlineFirst Publication

Autism benefits from OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our [OnlineFirst Fact Sheet](#)

[Back to top](#)

11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

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[Back to top](#)